



PHD

An investigation into the impact of dementia on couples and how they cope with this

Foster, Louise

Award date:
2012

Awarding institution:
University of Bath

[Link to publication](#)

Alternative formats

If you require this document in an alternative format, please contact:
openaccess@bath.ac.uk

Copyright of this thesis rests with the author. Access is subject to the above licence, if given. If no licence is specified above, original content in this thesis is licensed under the terms of the Creative Commons Attribution-NonCommercial 4.0 International (CC BY-NC-ND 4.0) Licence (<https://creativecommons.org/licenses/by-nc-nd/4.0/>). Any third-party copyright material present remains the property of its respective owner(s) and is licensed under its existing terms.

Take down policy

If you consider content within Bath's Research Portal to be in breach of UK law, please contact: openaccess@bath.ac.uk with the details. Your claim will be investigated and, where appropriate, the item will be removed from public view as soon as possible.

**An investigation into the impact of dementia on couples and how they
cope with this**

Louise Foster

A thesis submitted for the degree of Doctor of Philosophy

University of Bath

Department of Psychology

January 2011

COPYRIGHT

Attention is drawn to the fact that copyright of this thesis rests with its author. A copy of this thesis has been supplied on condition that anyone who consults it is understood to recognise that its copyright rests with the author and they must not copy it or use material from it except as permitted by law or with the consent of the author.

This thesis may be made available for consultation within the University Library and may be photocopied or lent to other libraries for the purposes of consultation.

Contents

<u>Tables and figures</u>	7
<u>Acknowledgements</u>	8
<u>Abstract</u>	9
<u>List of abbreviations</u>	10
1. <u>Chapter 1: Introduction to dementia</u>	11
1.1 Overview of dementia.....	12
1.1.1 <i>Diagnosis</i>	12
1.1.2 <i>Types of dementia</i>	13
1.1.3 <i>Progression and duration</i>	14
1.1.4 <i>Medication</i>	15
1.1.5 <i>Implications for UK</i>	15
1.2 Conclusion.....	17
2. <u>Chapter 2: The impact of dementia</u>	19
2.1 Impact on person with dementia.....	19
2.1.1 <i>The importance of the experience of people with dementia</i>	21
2.2 Impact on carer.....	24
2.3 Impact on relationship.....	29
2.3.1 <i>Impact on relationship from carers' perspective</i>	31
2.3.2 <i>Impact on relationship from couples' perspective</i>	33
2.4 Conclusion.....	36
3. <u>Chapter 3: Coping with dementia</u>	38
3.1 Coping in people with dementia.....	42
3.1.1 <i>Process of adjustment for people with dementia</i>	42
3.1.2 <i>Strategies used by people with dementia</i>	45
3.2 Coping in carers.....	47
3.2.1 <i>Process of adjustment for carers</i>	48
3.2.2 <i>Strategies used by carers</i>	53
3.3 Coping in relationships.....	56
3.3.1 <i>Process of adjustment for couples</i>	57
3.3.2 <i>Key features of couples coping with dementia</i>	61
3.3.2.1 <u>Awareness</u>	61
3.3.2.2 <u>Mutuality</u>	63
3.3.2.3 <u>Communication</u>	66

3.3.2.4 <i>Relationship-focused coping</i>	67
3.4 Conclusion	69
3.5 Aims	72
4. <u>Chapter 4: Methodology</u>	75
4.1 Research questions.....	75
4.2 Theoretical perspective.....	75
4.3 Definition of terms.....	76
4.4 Recruitment.....	78
4.4.1 <i>Inclusion criteria</i>	79
4.4.2 <i>Description of recruited sample</i>	81
4.5 Development of materials.....	82
4.5.1 <i>Development and piloting of interview schedules</i>	85
4.6 Data collection.....	87
4.6.1 <i>Setting</i>	88
4.6.2 <i>Prior to interview</i>	88
4.6.3 <i>During the interview</i>	89
4.6.4 <i>After the interview</i>	90
4.7 Data analysis.....	91
4.7.1 <i>Process of analysis</i>	92
4.8 Quality of the research methodology.....	97
4.8.1 <i>Sensitivity to context</i>	97
4.8.2 <i>Commitment and rigour</i>	99
4.8.3 <i>Transparency and coherence</i>	102
4.8.4 <i>Impact and importance</i>	103
4.9 Ethics.....	104
5. <u>Chapter 5: Results for people with mild dementia</u>	107
5.1 Impact.....	107
5.1.1 <i>Loss</i>	108
5.1.1.1 <i>Memory associated loss</i>	108
5.1.1.2 <i>Loss of ability in social situations</i>	111
5.1.2 <i>Identity</i>	112
5.1.2.1 <i>Initial reactions to diagnosis</i>	112
5.1.2.2 <i>Change in temperament</i>	114
5.1.2.3 <i>Enduring identity</i>	116

5.1.3 Relationship	117
5.1.3.1 <u>Role change</u>	117
5.1.3.2 <u>Communication</u>	119
5.1.3.3 <u>Being a burden</u>	122
5.2 Coping	124
5.2.1 Process of acceptance	124
5.2.1.1 <u>Attempts to explain</u>	125
5.2.1.2 <u>Reactions to day to day issues</u>	127
5.2.1.3 <u>Awareness</u>	129
5.2.1.4 <u>Reaching acceptance</u>	130
5.2.1.5 <u>Maintaining control</u>	132
5.2.2 Aids to coping	138
5.2.2.1 <u>Mental and physical activity</u>	139
5.2.2.2 <u>Recognising achievements</u>	143
5.2.2.3 <u>Attempts to maintain independence</u>	144
5.2.2.4 <u>Importance of social network</u>	148
5.3 Summary of Chapter 5	153
6. Chapter 6: Results for Carers	157
6.1 Impact	157
6.1.1 Impact on spouse with dementia	158
6.1.1.1 <u>Memory associated difficulties</u>	158
6.1.1.2 <u>Changes in their spouses' temperament</u>	159
6.1.2 Impact on carer	163
6.1.2.1 <u>Initial reactions to diagnosis</u>	164
6.1.2.2 <u>Responsibility</u>	165
6.1.2.3 <u>Worries/depressed</u>	167
6.1.2.4 <u>Feeling trapped</u>	171
6.1.3 Impact on relationship	174
6.1.3.1 <u>Changes to communication</u>	174
6.1.3.2 <u>Protect spouse</u>	177
6.2 Coping	179
6.2.1 Coping strategies	179
6.2.1.1 <u>Development of positive cognitions</u>	180
6.2.1.2 <u>Altering behaviours</u>	184

6.2.1.3	<i>Restoring normality</i>	187
6.2.2	<i>Maintaining feelings of couplehood</i>	189
6.2.2.1	<i>Existing methods of couplehood</i>	189
6.2.2.2	<i>New ways of maintaining couplehood</i>	192
6.2.3	<i>External support</i>	194
6.2.3.1	<i>Positive aspects of external support</i>	195
6.2.3.2	<i>Negative aspects of external support</i>	198
6.3	Summary of Chapter 6: Results for Carers	199
7.	<u>Chapter 7: Results for Couples</u>	204
7.1	Couples' understanding of dementia	205
7.1.1	<i>Role of medication</i>	207
7.1.2	<i>Ways of thinking about dementia for couples</i>	209
7.2	Maintaining a sense of normality	213
7.2.1	<i>Keeping active</i>	213
7.2.2	<i>Lessen the load</i>	222
7.2.3	<i>Direct discussion and support</i>	232
7.3	What indicated successful coping for couples?	240
7.4	Summary of Chapter 7: Results for Couples	242
8.	<u>Chapter 8: Discussion and conclusion</u>	246
8.1	Purpose of the study	246
8.2	Research question	246
8.3	Discussion	246
8.3.1	<i>How do people with dementia and their spouses describe the impact of mild dementia on their lives and relationship?</i>	249
8.3.1.1	<i>Changing identity</i>	252
8.3.1.2	<i>Changing relationship</i>	254
8.3.1.3	<i>Changing communication</i>	256
8.3.2	<i>What coping strategies are employed by people with mild dementia and their spouses?</i>	259
8.3.2.1	<i>Development of positive cognitions</i>	262
8.3.2.2	<i>Keeping active</i>	266
8.3.2.3	<i>Lessen the load</i>	269
8.3.2.4	<i>Direct discussion and support</i>	272
8.3.2.5	<i>Relationship continuum</i>	275

8.4 Summary and contribution to the literature.....	278
8.5 Professional/practice implications.....	286
8.6 Limitations.....	290
8.7 Further research.....	293
8.8 Conclusion.....	294
References.....	298
Appendix One: Sample Demographics.....	321
Appendix Two: Interview Schedule.....	324
Appendix Three: Information letter and consent form.....	327
Appendix Four: Example of a summary letter.....	332
Appendix Five: Ethical approval letter.....	335

Tables and figures

Figure 1: Procedure for data collection and analysis.....	87-88
Table 1: Sample demographics for Couples 1-4.....	321
Table 2: Background information for Couples 1-4.....	321
Table 3: Sample demographics for Couples 5-8.....	322
Table 4: Background information for Couples 5-8.....	322
Table 5: Sample demographics for Couples 9-12.....	323
Table 6: Background information for Couples 9-12.....	323

Acknowledgements

I would like to thank the participants of this study who gave their time so generously and graciously. Their honest, humble and engaging accounts meant that it has been a pleasure and honour to complete this work.

I would like to thank my two supervisors, Dr Karen Rodham and Professor Suzanne Skevington. Karen in particular deserves my heartfelt thanks for the many years of enthusiastic support and patience, for which I am truly grateful. Her continued belief in this thesis and support of my efforts to juggle my commitments has been fundamental to its completion.

I would like to thank my colleagues in the Older People's Mental Health Services in Swindon (especially the Memory Service in Swindon and North Wiltshire) for their invaluable support. I am very fortunate to work with such lovely and inspirational people. I would also like to thank Dr Roger Bullock for agreeing to fund the initial stages of this PhD.

Finally, and most importantly, I would like to thank my wonderful family without whom I could not have completed this thesis. My deepest thanks to my fabulous husband, James Foster, for always knowing exactly how best to support me, be it gentle encouragement to get on with it, or ensuring that I had some time away from it to allow me to enjoy simply being a wife and mother. I would also like to thank my two gorgeous boys, Tom (age 5) and Jack (age 3), who never fail to put a smile on my face. Heartfelt thanks also to my parents, Mary and John Cima, and parents-in-law, Norma and Alan Foster, for their unyielding emotional support and practical help over the duration of this PhD. I am aware of the sacrifices you have all made in support of me over the years, and I am very much looking forward to redirecting my energies back towards my family!

Abstract

Research into the lived experience of dementia, which has tended to focus on people with dementia and their spouses (carers) separately, has identified that spousal relationships play a crucial role in this experience. However, there is a lack of knowledge as to *how* the dyadic interactions in spousal relationships affect the experience of dementia for couples. This thesis aimed to address this gap by exploring how couples in which one partner had mild dementia described the impact of dementia and their attempts to cope with it. It was a qualitative study which followed the theoretical and methodological stance of Interpretative Phenomenological Analysis. Face to face semi-structured interviews were conducted with twelve couples, with each partner interviewed separately. Results illustrated that couples' reported their experience as a chronological process and were motivated to get on with their lives by maintaining a sense of normality. This study contributed to the literature by revealing how *both* partners experienced and coped with dementia, and the impact that their actions had on their spouse. Couples maintained normality through developing positive cognitions, keeping active, lessening the load and direct discussion and support. It was clear that couples' (particularly carers') awareness of dementia and its implications, *combined* with their knowledge of their spouse, affected how they experienced and coped with dementia. It was also clear that couples had different expectations about what constituted an acceptable level of communication, which thereby affected choice of coping strategy. The idea of a Relationship Continuum as a way to consider the impact of pre-morbid relationship styles on couples' responses to dementia was explored. Results were discussed in terms of existing knowledge and ways in which this thesis has added to the literature were highlighted. Professional and practice implications, limitations and future research were discussed.

List of abbreviations

‘PWD’ refers to the spouses who had dementia.

‘Carer’ refers to the spouses who did not have dementia.

The terms ‘spouse’ and ‘partner’ are also used and refer to both people with dementia and carers.

Chapter 1

Introduction: Dementia

The Department of Health (2004) say that 'chronic diseases are diseases which current medical interventions can only control not cure. The life of a person with a chronic condition is forever altered – there is no return to "normal" '. This definition, however, does not acknowledge that people with chronic illnesses often manage to continue successfully with their lives by adjusting to the problems associated with their disorder (Gilhooly 1984 and 1986, Gladstone 1995, Eloniemi-Sulkava, Notkola, Hamalainen, Rahkonen, Viramo, Hentinen, Kivela and Sulkava 2002, Kralik 2002, Clare 2003, Stanton, Revenson and Tennen 2007, Sabat and Gladstone 2010). As the population ages and the percentage of the population with chronic illness, such as dementia, increases (Alzheimer's Society statistics 2007, UK National Dementia Strategy, 2009), it is important to increase our understanding of the lived experience of these diseases in order to learn how individuals cope and adjust to the difficulties presented by their condition. An increased understanding of successful coping strategies may help professionals to develop effective interventions for people with a chronic illness.

Over the last few years, the UK Government has become increasingly aware of the likely impacts that an ageing population will bring. In particular, the impact of increasing numbers of people with dementia (a chronic illness that most commonly affects people over 65), means that dementia related policies are at the forefront of these plans. At present there are 700,000 people with dementia in the UK and this is set to rise to over one million by 2025 (Alzheimer's Society statistics 2007, UK National Dementia Strategy, 2009). The Dementia UK Full Report (Knapp, Prince and Albanese et al 2007) outlined that dementia generally afflicts an older population, with one in fourteen people over the age of 65 being affected, rising to one in six in people over 80 years old. Despite this however, there are at least 15,000 people under the age of 65 who have the illness (UK National Dementia Strategy, 2009). The ways in which governments are set to manage this issue is of

worldwide concern with global costs associated with dementia predicted by the World Alzheimer Report 2010 to amount to more than 1% of the world's gross domestic product in 2010. Therefore, the authors of the report are urging Governments to make dementia a priority for funding.

This thesis explores in depth the lived experience of dementia for couples. The importance of research into relationships in dementia is recognised by the National Institute of Clinical Excellence (NICE) who identified the impact of dementia on relationships as a 'core principle of care' (Daniels, Lamson and Hodgson 2007). Furthermore, in the absence of a cure, it is important that researchers aim to improve understanding of the lived experience of dementia as these findings may then be developed into appropriate and efficacious interventions that help people with dementia and their families to *live well with dementia*, as is the focus of the UK National Dementia Strategy published by the Department of Health in 2009.

1.1 Overview of dementia

Knapp and colleagues (2007) specified that dementia affects memory, reasoning and communication skills, which results in a declining ability to carry out daily activities. Alongside this decline, "individuals may develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering, which complicate care and can occur at any stage of the illness" (UK National Dementia Strategy 2009). At present, this disease is irreversible.

1.1.1 Diagnosis

NICE (2006) guidelines on dementia state that diagnosis should only be made following a comprehensive assessment of the patient, involving history taking, cognitive and mental state assessment, physical examination and a review of medication. If dementia is still suspected, further investigations such as blood tests, urine sample, brain imaging and formal neuropsychological assessment are recommended.

Currently only a third of people with dementia actually receive a formal diagnosis, or even have any contact with secondary care specialist services such as a memory clinic during their illness (UK National Dementia Strategy 2009). Diagnosis can often occur too late for the use of acetylcholinesterase inhibitors (medications licensed for use with Alzheimer's disease), and/or in response to a crisis. Late diagnosis makes it more difficult to support people to 'live well with dementia'. Living well is the primary focus of the UK National Dementia Strategy. Furthermore, people who are not yet diagnosed with dementia do not get the chance to make informed choices about the future nor access to interventions that may help them, and neither do their families.

Two thirds of people with dementia live in the community and often this is only made possible through the efforts of family members and carers who support those people (Alzheimer's Society statistics 2007). Therefore, research should endeavour to include both the person with dementia and others who are affected, in order to fully address the experience of dementia, and therefore provide the most appropriate interventions.

There is therefore a need to improve the process of accurate diagnosis, for instance by effective liaison with primary care and promoting awareness of dementia generically, if the numbers of people diagnosed earlier are to be increased. Furthermore, at present, with only a third of people with dementia receiving a formal diagnosis (UK National Dementia Strategy 2009), the demand on services is set to rise on two fronts, due to both improved diagnostic procedures and increasing numbers of dementia as per the ageing population.

1.1.2 Types of Dementia

The most common form of dementia is Alzheimer's disease, which accounts for 62% of dementia cases (Knapp et al 2007). No one single cause has been attributed to the development of Alzheimer's Disease and at present, it is thought to be a combination of a number of factors including older age,

genetics, environmental factors, diet and overall health (Alzheimer's Society 2010). Alzheimer's disease is a physical disease of the brain which sees the development of 'plaques' and 'tangles' which lead to cell death. The second most common form is Vascular dementia, which accounts for 27% of all dementia cases (Knapp et al 2007). Vascular dementia is caused by either a stroke (single-infarct dementia) or a series of small strokes (multi-infarct dementia). As such, the symptoms can occur suddenly or more gradually. Risk factors that may lead to stroke include high blood pressure and cholesterol, heart problems, diabetes, limited physical activity, high levels of alcohol and smoking, and poor diet (Alzheimer's Society, 2010). Other damage to the brain structure can also produce dementia-like symptoms. Much rarer causes of dementia include Creutzfeld-Jacob disease and Korsakoff's Syndrome (Kitwood, 1997).

A further diagnosis called Mild Cognitive Impairment (MCI) is given when people demonstrate some of the symptoms associated with dementia such as short term memory loss or difficulties comprehending information, but these symptoms are not acute enough to constitute the diagnosis of Alzheimer's disease (Alzheimer's Society 2010). For most people with MCI, their difficulties do not progress; although 10-15% of people with MCI will go on to develop Alzheimer's disease.

1.1.3 Progression and duration

The dementias are progressive in nature and therefore over time "the person's ability to remember, understand, communicate and reason will gradually decline" (Alzheimer's Society, 2010). As people with dementia move through the three stages (mild, moderate and severe dementia) they will require increasing amounts of care. Although dementia is a terminal illness, people can live with it for 7-12 years after diagnosis (UK National Dementia Strategy 2009).

The Alzheimer's Society (2010) lists the common signs of mild stage dementia as including forgetting about recent conversations/events, repetitive speech,

finding it more difficult to grasp new ideas, confusion, losing interest in other people or activities, blaming others for mislaid items and being unwilling to try new things. NICE (2006) suggest that mild dementia is represented by a Mini Mental State Examination (MMSE) memory assessment score of 21-30 (Folstein, Folstein and McHugh 1975). The MMSE is a widely-used screening assessment in the field of dementia where a score of 30 out of 30 would indicate no cognitive impairment, whereas a score of 0 out of 30 would indicate severe cognitive impairment.

1.1.4 Medication

At present there are four medicines licensed for use with Alzheimer's disease following recommendations by NICE (2006), updated draft guidance is undergoing consultation at the time of writing. These are Donepezil, Rivastigmine, Galantamine and Memantine. The first three medications are acetylcholinesterase inhibitors which prevent the acetylcholinesterase enzyme from breaking down acetylcholine which acts as a chemical messenger in the brain. Memantine works in a different way to the other three medications, by blocking a messenger chemical called glutamate. Rivastigmine is also licensed for use with Parkinson's related dementia and Lewy Body Dementia (NICE 2006). However, there are no licensed treatments for other types of dementia. In the case of Vascular Dementia, the Psychiatrist or Geriatrician will advise on efforts the patient can make towards further stroke prevention such as hypertension, diabetes, smoking, alcohol consumption and hypercholesterolemia. In addition, supplements such as Vitamin E, Ginkgo Biloba and Ginseng have also been trialled for use in people with dementia.

1.1.5 Implications for UK

In 2009 the Department of Health published "Living Well with Dementia: A National Dementia Strategy - implementation plan" in which it set out 17 objectives in order to meet the demand of increasing numbers of dementia cases, and also to ensure the best possible care for people with dementia. It was argued that if all 17 objectives were addressed at a local level across the

UK this would mean that people with dementia and their families would have a greater chance of 'living well with dementia'. Of particular relevance to this thesis are the following two objectives:

Objective 2: Good-quality early diagnosis and intervention for all.

This objective is concerned with installing efficient and effective pathways of care that are accessible to all and ensure an accurate and sensitive assessment and diagnosis, with the provision of suitable treatment, care and support following diagnosis.

Thus there is a need for research to focus on the lived experience of people with dementia and their spouses in order to help ensure that interventions aimed to support them are developed in terms of what may be most beneficial to this population.

Objective 16: A clear picture of research evidence and needs.

This objective sets out that evidence that contributes to the existing research base in the UK should be accessible, and that future research should concentrate on bridging the gaps in knowledge.

The proposed outcome of the UK National Dementia Strategy is the commission of specialist services that will provide early assessment, diagnosis and intervention. It is likely that memory clinics will perform this role, and means that there will be more emphasis on providing effective support to people with dementia and their carers, compared to the traditional prescribing-based clinics.

Indeed, this mood of change is not limited to the UK National Dementia Strategy, and has in fact been central to many of the Government policies that have been developed with regards to dementia in the last ten years. For example, both the Department of Health's National Service Framework for Older People (2001) and Everybody's Business (2005) advocated early diagnosis and meaningful intervention. This move away from stigma and towards a more positive approach to the diagnosis of dementia also means

that there will potentially be more people diagnosed with mild dementia, since the current trend is to under-diagnose (UK National Dementia Strategy, 2009).

1.2 Conclusion

Dementia as a term represents a group of diseases that are both irreversible and progressive in nature. The numbers of people with dementia are set to rise rapidly in the coming years both with improved early diagnosis and with an ageing population. This means that more and more people will be living with or caring for someone with dementia. The UK National Dementia Strategy (2009) outlined the importance of providing suitable and effective support as it is required, and the development of such interventions will be enhanced through increasing our understanding of how people with dementia and their loved ones experience and cope with dementia.

In order to do this, it is important to yield input from both people with dementia and their loved ones if we are to truly understand their experiences. Indeed, the research community has now generally accepted that people with dementia can offer reliable and valid input into research, so there is no reason to dismiss them. Furthermore, there are still areas of research, such as into the impact of dementia on couples that require further input from all affected parties.

The next two chapters provide the reader with an overview of the existing knowledge base concerning first the **impact** of dementia on the person with dementia, on their carer, and on couples, and then how people with dementia, carers and couples **cope** with dementia. This approach reflects the way in which de Boer, Hertogh, Dries, Riphagen, Jonker and Eefsting (2007) structured their literature review on the patient's perspective of having dementia, and is therefore in keeping with the ways in which research into the experience of dementia is presented in the literature.

- **Chapter One** has provided definitions of chronic illness and dementia and has discussed the present climate for people with dementia and their families within the UK.
- This began with a discussion of the diagnosis of dementia, followed by an introduction to different types of dementia.
- Consideration of the progression and duration of dementia highlighted the importance of family members in the experience of dementia.
- The reader was introduced to pharmacological advances in dementia care, including the recent decision by NICE to extend the use of acetylcholinesterase inhibitors to those with mild, as well as moderate dementia.
- Furthermore, knowledge about the needs of couples facing dementia is limited because research in this area has tended to focus either on the person with dementia, or more commonly the carer rather than including both spouses equally.

Chapter 2

The Impact of dementia

This chapter focuses on research that has attempted to further understanding into the impact of dementia. This will be done by first considering the impact for people with dementia, then the impact on their carers and finally, the impact on relationships.

Although this review centres upon research into dementia, research into other chronic illnesses has also been included. The reason for this is due to the fact that people with dementia have not historically been included directly in research (as discussed later in Chapter 2). This means that there is less research into the impact of dementia from the point of view of the person with the illness compared to other chronic illnesses such as cancer and chronic pain, where the impact on people with the disease is better understood. Where this research was considered to be useful for understanding the role that chronic illness plays in a person's life, it was included in this review.

2.1 Impact on person with dementia

Across the dementia field, research has historically focused on impact on spouses and families as opposed to people with dementia. Indeed, even where people with dementia have been included in research they have not often played an active and equal role in the research when compared to their carers (Daniels et al 2007). This is problematic since people with dementia are likely to encounter different experiences and face different stressors when compared to their spouse or family.

The experience of being diagnosed with chronic illness is often defined by feelings of vulnerability and shock in recognition that suspecting the diagnosis is markedly different to having it confirmed (Kralik, Brown and Koch, 2000). In support, a study into the attitudes of people with mild dementia, Pinner (2003) found that only 28% of participants had insight into the fact that they may have

dementia. This was in spite of the fact that they were attending a memory clinic at the time of the research. Furthermore, diagnosis can represent a time of heightened emotions which can often be more disabling, at least in the short term, than the illness itself (Lewis 1998, Kralik 2002, Kralik et al 2000). Similarly, some of the emotions experienced by people with other chronic illnesses around the time of diagnosis do lessen in severity and/or are replaced by other emotions as time goes on (Rabins, Fitting, Eastham and Zabora, 1990, Halford, Scott and Smythe, 2000). Therefore the negative emotions associated with diagnosis are not necessarily sustained for the long term. Furthermore, despite the potential for shock and distress, Kralik et al (2000) reported that some participants in their study reported a sense of validation because the diagnosis provided an explanation as to what was happening to them. What does appear to be the case is that following diagnosis, there is a period of adjustment in which individuals try to come to terms with it and work out ways to live with it (Vernooij-Dassen, Derksen, Scheltens and Moniz-Cook 2006). This period during which individuals attempt to incorporate dementia into their lives involves the successful negotiation of tensions such as acknowledging the diagnosis and maintaining a sense of identity (Harman and Clare, 2006).

Chapter 1 explained that the outcome of dementia is inevitably that “the person’s ability to remember, understand, communicate and reason will gradually decline” (Alzheimer’s Society 2010). Whilst this definition does not mention the psychological side effects associated with this decline, researchers historically have acknowledged the negative implications for people with dementia that accompany them in this process. For example, people with dementia are more likely to be depressed when compared to their carers (Burns, Jacoby and Levy 1990) and feel powerless (Proctor 2001). Similarly, research into personality changes in people with dementia shows that anxiety, depression and vulnerability increase whilst warmth, assertiveness, and openness decrease (Chatterjee, Strauss, Smyth and Whitehouse, 1992, Welleford, Harkins and Taylor, 1994, Garner, 1997).

This may be in part due to difficulties engaging in social communication and communicating with the world around them as a whole, which can encourage people with dementia to withdraw into themselves, which may explain feelings of depression, vulnerability and anxiety outlined above (Cumming and Henry, 1961). A further explanation is linked to the theory of attachment which suggests that attachment behaviours come into force when a person's security and safety is threatened (Markiewicz, Reis and Gold 1997). Thus a diagnosis of dementia or the development of more severe dementia may cause a breakdown in the attachment techniques the individual has developed, which can leave them feeling helpless, vulnerable and in fear of abandonment, (George and West, 1999). These feelings can also manifest in the behaviour of those with mild cognitive impairment such as proximity-seeking behaviour whereby individuals seek the physical company of another person in order to feel safe (Wright, 1991, Shields, Travis and Rousseau, 2000). However, the role of attachment in dementia and in older people in general, is not fully understood (Koski and Shaver 1997, Shields, Travis and Rousseau 2000).

These different theories offer some insight into the reasons why people with dementia might develop feelings of depression, anxiety and vulnerability, and together they offer some hope that input from others or better understanding of dementia may improve people with dementia's experience of the disease. However, whilst understanding the reasons for changes is important, it does not take away the fact that these changes happen and that they can be difficult to cope with.

2.1.1 The importance of the experience of people with dementia

Kitwood (1997) was one of the first researchers to insist on viewing people with dementia as individuals and recognising that their sense of 'personhood' endures despite dementia. Indeed, while it may be accepted now that people with dementia might feel depressed, anxious or vulnerable, these factors are no longer believed to define the experience of having dementia. For example, Westius, Andersson and Kallenberg (2009) interviewed 21 people with mild to moderate Alzheimer's disease and using a phenomenological hermeneutic

approach found that they were able to recall memories which represented their central values and basic attitude to life, both of which were components in their view of life. Furthermore, Caddell and Clare's (2010) systematic review of studies into self and identity in dementia found evidence for the continued existence of people with dementia's personal identity, their own beliefs and attributes, as well as their multiple social personae. These three elements of self make up the Social Constructionist model of self as defined by Sabat and Collins (1999). Therefore, recent research presents evidence that is in stark contrast to research that accepted that people with dementia withdrew into themselves once they could no longer contribute within a social setting (Chatterjee et al 1992, Welleford et al 1994, Garner 1997). Indeed, many of the stereotypes associated with dementia in past years have since been quashed.

To illustrate further, Westius, et al (2009) found that the memories described by the people with dementia were often significant anecdotes that were either powerful emotionally such as memories of childhood or representative of values, such as role models. Therefore, the conclusions are twofold in that people with mild to moderate dementia can articulate their view of life, and also therefore, that their central values and basic attitude to life remain stable despite dementia. In tentative support, Sabat and Gladstone (2010) reported on the intact social cognition and social behaviour in one lady with moderate Alzheimer's disease.

It is also important to remember that the impact of dementia should be determined within the context of an individual's life because everyone is different and the same stressors can impact differently on people (Zarit, Johansson and Jarrott, 1998, Keady, Williams and Hughes-Roberts, 2007, Westius et al 2009). This has practical implications for healthcare professionals, for example with regards to the provision of information offered to people with dementia. Indeed, Harman and Clare (2006) found that people with early-stage dementia felt that it was important that they were offered a choice about how much information they were given about dementia. The

authors argue that for some people it is helpful but for others too much information can hinder successful adjustment.

It is also important for healthcare professionals to understand that people with dementia may feel differently about taking acetylcholinesterase inhibitors medication which may help slow the progression of their dementia. Hutchings, Vanoli, McKeith, Brotherton, McNamee and Bond (2010) interviewed twelve older people who had been referred for memory problems, or who had been diagnosed with Alzheimer's disease, about their experiences and perceptions of acetylcholinesterase inhibitors. They found this sample reported improvements in dementia-related difficulties such as forgetfulness, and that they also appreciated the stabilising effect that they perceived the medication to have. In fact, the authors reported that this sample hoped that taking these medications may return their lives to something resembling normality. These findings were in some ways different to findings from carer focus groups, which will be reported in the 'carer' section of this chapter. This again highlights the importance of upholding individuality, not only with regards to people with dementia and carers as individuals, but also respecting individuality within the same couple/family.

Indeed, acknowledgement of the importance of the individual in understanding the impact of dementia is now reflected in the research methods available for studying this issue. In 2007, Keady and colleagues reported on their newly developed qualitative research method called Co-constructed Inquiry, in which a person with dementia creates their 'life story script' along with a healthcare professional. Following this, the person with dementia and healthcare professional use this life script to attribute meaning to certain events or feelings which they use to produce a 'personal theory' and then ultimately a 'collective theory' which covers a number of cases across that person's life. The authors argue that this process helps the person with dementia to understand the impact that dementia has upon them in the context of the way in which they have dealt with issues across their lives. (This is discussed regarding coping in Chapter 3, p49.) This reflects a truly person centred

approach to engaging with people with dementia, which is in keeping with the current perspective in dementia care.

2.2 Impact on carer

To date, the majority of research on the impact of dementia has focused on the carers of people with dementia. In the UK, it is usually spouses or family members who take on most of the caring responsibilities for their loved one (Alzheimer's Society 2010). In addition to the responsibility of caring for someone, carers may also seek to adhere to socially constructed ideals such as avoiding institutionalisation whereby entry to care homes is considered by many to be the absolute last option. This means that carers often keep their loved ones at home despite the occurrence of multiple difficulties such as wandering, aggressive behaviour and/or incontinence.

Gates (2000) defined the experience of caring for a loved one as: "the meaning of caring for an elderly relative is surfacing poignant remembering while doggedly continuing with nurturant giving and confirmatory receiving, as swells of enjoyment merge with tides of sorrow amid uplifting togetherness and valleys of aloneness" (p.54). This illustrates that caring for a loved one can be both a positive and negative experience. Furthermore, Carpenter and Mak (2007) reported that caring for a loved one with dementia, holds two extra psychological challenges: the first is related to the large amount of information that carers have to take on board in order to care effectively with regards to the disease itself and also the legal and practical implications associated with dementia. The second is the fact that carers both anticipate and experience the deterioration of their loved one. Therefore, caring for someone with dementia holds specific demands in addition to those associated with chronic illness generically.

The roles that a person adopts as a 'carer' will depend on the relationship they have with their loved one. Caring for a spouse will be different to caring for a parent, sibling or friend, and these differences are reflected in the responsibilities they create. For example, adult children caring for their parents

often have families of their own and therefore have competing responsibilities which can be difficult to manage. Furthermore, carers who still work will also have to juggle working life with ensuring their loved one is as safe and well as possible. Research shows that a carer's gender may also influence how they respond to their spouse having a chronic illness. Generally, research has found that females exhibit more distress in their caring role than males (Blanchard, Albrecht and Ruckdeschel 1997, Baider, Kaufman and Peretz 1996) which may in part be due to the societal pressures to conform to the stereotype of a caring wife (Orbell 1996).

What is clear is that whilst dementia obviously has an impact on those with the disease, it also affects the wider family, and particularly the main carer. Zarit et al (1998, p.348) explain that "...there is no single caregiver stress or burden but, rather, a broad array of potential stressors", which suggests that each carer has a different experience of dementia. This may be due to practical issues such as the stage of dementia, or the presence of behavioural difficulties, but it may also be determined by the important fact that each individual may attribute different levels of importance to different stressors.

Responses to a loved one being diagnosed with dementia are centred on anxiety and anger (Rabins et al, 1990) but that the severity of these emotions lessens over time (Rabins et al, 1990, Halford et al 2000). Much of the research into the impact of dementia for carers has historically focused on the negative impacts (Gates 2000, Garand, Dew, Eazor, DeKosky and Reynolds, 2005). By also reviewing research into other chronic illness and the impact on carers, this has revealed similarities across chronic illnesses. For example, in one study which combined carers of people with dementia, stroke and Huntington's disease, Thommessen, Aarsland, Braekhus, Oksengaard, Engedal and Laake (2002) found similar levels of psychological burden among carers in all three groups. The carers in these groups associated burden with practical changes such as changes to routine, holidays, social life and sleep patterns. Furthermore, research has identified that carers often report a decrease in pleasurable activities in part due to increased responsibilities as their loved one may be less able to contribute (Clark and Bond 2000,

O'Shaughnessy, Lee and Lintern 2010). This can lead to feelings of a 'shrinking life' as identified by Ohman and Soderberg (2004).

Other studies have reiterated the difficulties facing carers in the successful management of disruptions to daily life, and as a result explained why this often becomes one of the main motivations for carers (Blanchard et al 1997, Ohman and Soderberg, 2004). However, it seems that caring responsibilities can have consequences for carers because they are often under chronic strain and may have high expectations of themselves in their caring role, which means that they are at risk from burnout, (a state of physical and emotional exhaustion) (Almberg, Grafstrom and Winblad, 1997) or at least experiencing tension between meeting their own needs and those of their spouse (O'Shaughnessy et al 2010). Other research suggests that the presence of behavioural problems in the person with dementia is significantly related to feelings of burden and strain in the carer (Coen, Swanwick, O'Boyle and Coakley, 1997, Searson, Hendry, Ramachandran, Burns and Purandare 2008) and is also adversely related to relationship quality (de Vugt 2003, Zarit and Edwards, 2008). Therefore, it is clear that there are a number of factors that could create feelings of strain and burden in carers.

With regards to the emotional impact on carers, feelings of helplessness have been documented in research into Alzheimer's disease (Laakkonen, Raivio, Eloniemi-Sulkava, Saarenheimo, Pietila, Tilvis and Pitkala 2008). Fears and anxieties regarding the future are also well represented in the literature across chronic illnesses (Williams, Briggs and Coleman 1995, Blanchard et al 1997, Laakkonen et al 2008, O'Shaughnessy et al 2010).

Research specifically into dementia has highlighted further emotional impacts for carers such as loneliness and depression (Jones and Martinson 1992, Ott, Sanders and Kelber 2007, Laakkonen et al 2008), stress (Eagles, Craig, Rawlinson, Restall, Beattie and Besson 1987) and guilt (Rabins et al 1990, O'Shaughnessy et al 2010).

There has also been some work that has acknowledged the impact of dementia on carers' grieving (O'Donnell 2000, Laakkonen et al 2008). Remembering that dementia is a degenerative disease with regards to reasoning and memory and is accompanied by a progressive series of losses, Ott et al (2007) argued that the severity of grief experienced by carers increases over the duration of the disease, and also that because of these progressive losses the experience of dementia for carers is different to that of other chronic illnesses.

The concept of anticipatory grief in which the 'well' spouse unconsciously mourns their partner can help carers to be emotionally prepared for when their spouse actually dies (Theut, Jordan, Ross and Deutsch 1991, Baikie 2002). Garner (1997) referred to this phenomenon as a coping mechanism which importantly allows carers the time to resolve their relationship if necessary. Garner also found that grieving for current losses was a fundamental element of carers' grieving in addition to considering anticipated losses. Grieving over current losses was also defined by Jones and Martinson (1992) as 'dual dying grief' in which carers observe a series of losses to both the intellectual and social dimensions of their partner, hence the 'dual' aspect. Therefore, although carers can grieve in response to their partner's dementia, this is not necessarily destructive to their overall adjustment if it means that they are better prepared for their spouse's eventual death, and indeed the progressive losses which lead to that event. Indeed, De Vugt (2003) found that despite a reported deterioration of their relationship, carers also reported feeling closer to their spouses than before. This may be attributed to successfully navigating at least some of the difficulties associated with dementia, the reality of dementia encouraging a better appreciation of their relationship, or perhaps feelings of empathy towards their spouse which induce feelings of protection in the carer.

Whilst considering the impact of dementia on carers, acknowledging the relationship that the carer holds with their loved one is also crucial for understanding their experience. Indeed, it is important that researchers and health care professionals remember that carers not only have to deal with the

practicalities associated with having a loved one with dementia, but also acknowledge the impact of dementia on them as people, wives, husbands, sons and daughters etc. Some researchers propose that changes to the carers' relationship with the person with dementia can be more challenging to carers than the practical demands associated with dementia, even if those demands are high. For example, losses associated with the relationship, be it losing a problem solver or discussion partner (Ingebretsen and Solem 1998) can be difficult for carers to come to terms with.

However, despite the apparent difficulties associated with caring for someone with dementia, it is also important to note that a good deal of research has also reported positive findings related to the responses of carers (Gilhooly 1984 and 1986, Rabins et al 1990, Narayan, Lewis, Tornatore, Hepburn and Corcoran-Perry 2001). More recently, high relationship satisfaction among carers of people with dementia was associated with significantly less burden and reactivity to memory and behaviour problems, and better problem solving skills and communication compared to spouses with low relationship satisfaction (Steadman, Tremont and Duncan Davis 2007). Therefore, relationship satisfaction is potentially important in the defence against feelings of burden for carers. Furthermore, it is also important to remember that positive and negative aspects of caring exist concurrently, and thus the existence of difficulties around the caring role does not preclude the existence of positive experiences (Narayan et al 2001).

Recent research has highlighted two further areas for investigation with regards to carers of people with dementia. Firstly, Quinn, Clare, Pearce and van Dijkhuizen (2008) indicated that relatively low attention has been paid to the subjective account of carers when their loved one has dementia, and indeed the majority of the studies mentioned above have relied predominantly on quantitative measures. Researchers are beginning to address this imbalance. For example, following quantitative evidence from clinical trials that the use of acetylcholinesterase inhibitors may reduce carer stress (Cummings, Schneider, Tariot, Kershaw and Yuan 2004), Hutchings et al (2010) reported on the subjective experience and perceived impact of acetylcholinesterase

inhibitors for people with dementia and their carers. Their study found that carers were keen to try anything with regards to treatment for their loved ones. It was reported that carers felt positive that something was being done against dementia, although they did not always see the direct benefits that were reported by treatment users in the same study, such as a decrease in forgetfulness. Furthermore, the act of ensuring compliance with medication was sometimes tricky for carers, particularly if they did not live with their loved one. Despite this however, carers felt that acetylcholinesterase inhibitors were the 'lesser of the evil' (Hutchings et al 2010, p.418). Their study takes an important step into understanding the subjective experience of dementia, and with it, the experience of medication. However, Hutchings and colleagues did not attempt to access the dyadic features of this experience. This criticism is upheld by Braun, Scholz, Bailey, Perren, Hornung and Martin (2009) who argued that although much research has been undertaken into the impact of caring for someone with dementia, how these impacts are influenced by the person with dementia or dyadic features of their relationships is yet to be fully understood. Given the differences reported by treatment users and their carers, it would be important for future research to try and bridge this gap, and further understanding of the lived experience of medication in dementia, and indeed the experience in general, within couples and families.

2.3 Impact on relationship

As the person with a chronic illness experiences changes regarding what they can manage, families often find that roles in the family and home become altered (Blanchard et al 1997, Schwartz and Ehde 2000, Sormanti and Kayser 2000, Carpenter and Mak 2007) and boundaries can become blurred (Patterson and Garwick 1994). This may transpire, for example, where the person with the disease is less psychologically available to their family, or where conflict exists regarding the reassignment of household roles (Bramwell 1986). Chronic illness is indeed thought to offer several challenges for relationships including reduction in shared activities, redistribution of roles and responsibilities, changes in autonomy, perceived inequalities and changes in role expectancies (Lyons, Sullivan and Ritvo 1995). Within close relationships

in dementia, this means relationships become unbalanced (de Vugt 2003, Carpenter and Mak 2007) due to disorganisation, uncertainty, tension, loss of intimacy, mutuality and neglect of the companion part of the relationship (Wright 1991, Quayhagen and Quayhagen 1996, Clarke and Watson 1991, Gallagher-Thompson, Dal Canto, Jacob and Thompson 2001, Eloniemi-Sulkava et al 2002, Knalf and Gilliss 2002).

Although simplistic, equity theory (Walster, Walster and Berscheid 1978b) is a useful way of thinking about the impact of dementia on relationships. It assumes that relationship satisfaction is achieved when the rewards from a relationship outweigh the costs, and therefore it is possible that relationship satisfaction may be compromised with the introduction of potential 'costs' such as dementia. Equity theory surmises that caring for a loved one is a cost since taking on a caring role can compromise reciprocity (Neufeld and Harrison 1998, Quinn, Clare and Woods, 2009) and the balance of contributions within a relationship, the maintenance of which are vital to relationship satisfaction. When inequity exists in a relationship, Braun et al (2009) suggest that individuals will experience distress, although this may not necessarily affect the overall relationship quality (Quinn et al 2009). Therefore, it is unlikely that equity theory can account for all variances, although it does offer some insight into the impact of dementia within relationships.

Most research that considers the impact of dementia on the marital relationship has followed the overarching trend in dementia research by focusing on the carers' perspective. Furthermore, there is a lack of research that focuses on the impact on the marital relationship from the person with dementia's perspective. Indeed, Carpenter and Mak (2007) recommended that as some elements of caregiving are dyadic in nature, that research which focuses on transactions within couples is more likely to provide valid analysis of these features than research which only focuses on one perspective.

2.3.1 Impact on relationship from carers' perspective

Kaplan (2001) reported reduced feelings of couplehood for spouse carers following a diagnosis of dementia. Consequently, research in dementia has made some attempts to further understand how partners may influence the impact of dementia on each other. For example, carers found the presence of behavioural problems in their loved one to be more difficult to adapt to when compared to cognitive or functional problems and as a result, the presence of behavioural problems was found to be adversely associated with relationship quality for the carer (de Vugt 2003, Zarit and Edwards 2008). De Vugt found this was particularly the case when apathy was exhibited by the partner with dementia because it meant that frequency and reciprocity of interactions between partners was compromised.

Gallagher-Thompson et al (2001) also made a connection between caring for a spouse with dementia and reduced reciprocity as well as fewer shared pleasurable activities, less hope and sense of agency, and more stress and depression when compared to wives whose husbands did not have dementia. Furthermore, the wives whose husbands did have dementia (compared to wives whose husband did not have dementia) were also generally less facilitative and supportive towards their husbands. Encouragingly though, the authors also found that there were no differences between these two groups on ratings of closeness and shared values. Therefore, although it appears that dementia can have an adverse effect in some areas of the marital relationship, it is heartening that not all areas appear to be affected.

Indeed, the inevitability with which it is sometimes assumed that marital relationships in dementia cannot endure is not always founded. Two studies that were conducted on carers whose spouses with dementia lived in an institution are a case in point. First, 66% of carers interviewed by Gladstone (1995) reported that their marriage was 'happy' despite their spouse being in an institution. Second, 44% of carers interviewed by Kaplan (2001) continued to define themselves as 'we' despite the fact that their spouse had severe Alzheimer's disease and was living in an institution. These studies suggest that

while the presence of dementia may initiate some changes in marital relationships, marital decline is not inevitable.

Further research has attempted to address how carers continue to be 'happy' or consider themselves a 'we' despite their spouse's dementia. Neufeld and Harrison (1998) identified two types of caring where one was linked to reciprocity and the other was linked to feelings of obligation. Caring associated with reciprocity was most conducive for the development of positive feelings in the carer and in particular, 'constructed reciprocity' in which the carer attended to non-verbal cues to maintain a level of communication and therefore reciprocity with their loved one. Conversely, caring associated with obligation was replete with feelings of burden, stress, anger, loneliness and frustration (Neufeld and Harrison 1998). Other studies have also confirmed that feelings of obligation can impede the development of positive carer feelings (Swensen and Trahaug 1985, Lewis, 1998).

However, feeling 'happy' does not seem to be essential for the existence of positive feelings in carers. For example, despite reporting a decline in happiness, carers also reported that the general atmosphere of their marriage remained unchanged (Eloniemi-Sulkava et al 2002). It is also worth noting that despite the negative implications associated with obligation, 54% of the male carers in Neufeld and Harrison's (1998) study cared for their wives out of feelings of obligation without any reciprocity. However, it is possible that this may reflect a male-orientated interpretation of caring for a spouse with dementia.

Further factors to consider include the quality of the premorbid relationship whereby a good quality past relationship may actually make the impact of dementia more difficult to cope with. A number of studies have found that couples with better premorbid relationships experience more feelings of loss, perhaps because they have more to lose (Lewis 1998, Strawbridge, Wallhagen, Thai and Shema 2009). This may be associated with declines in communication that are sometimes experienced in couples facing dementia, since carer wives who valued good communication within their premorbid

relationships were more likely to have good premorbid relationships (Strawbridge et al (2009)).

Clearly then, the impact of dementia on relationships from the carers' perspective is evidently not yet fully understood, and further work should be undertaken. In support, Quinn et al (2008) commented on the lack of attempts by researchers to access the subjective stories of carers of people with dementia, and as a result they interviewed 34 partners of people with mild dementia in order to gain insight into their understanding of their situation. The authors found that the carers had some difficulty understanding things that were happening and were aware of changes to their relationship. They also found that lack of understanding meant that carers responded in ways that added to their difficulties and arguably reduced their sense of well being. Therefore, the role of healthcare professionals and research could be to enhance understanding which may in turn improve marital interactions

Of course, more work needs to be done to address the dynamics of couples in determining their experience. A decade ago Kaplan (2001) commented that '...an understanding of how caregiving affects the marriage has not yet been achieved' (p.87). There have certainly been many efforts made by researchers to bridge this gap in understanding, although recent studies have recognised the necessity for involvement of both partners in research in order to achieve both perspectives and learn more about how these perspectives interact (Quinn et al 2008, Braun et al 2009).

2.3.2 Impact on relationship from couples' perspective

Research has attempted to address the impact of dementia on couples, but few studies have included the person with dementia and carer as equally active research participants who were studied together or simultaneously (Daniels et al 2007). This is problematic since the impact of dementia is different for people with dementia and their carers even though they are part of the same relationship. Furthermore, Braun et al (2009) conducted a review of research into the dyadic perspective of dementia within a spousal relationship

and indicated that “relatively little is known about how caregiver and care receiver variables interact” (p.426) and suggest that “studies actually referring to both partners are indeed the only possibility to get insight into caregiving dyads” (p.428). Indeed, their review illuminated only a small number of studies that directly included both the person with dementia and their spouse.

It should be noted that of five studies that Braun et al (2009) discussed in depth, they all used quantitative measures (sometimes in addition to qualitative methods) to gain insight into the interactions between people with dementia and their spouses. The use of quantitative methods arguably has implications regarding the levels of insight that researchers could hope to achieve due to the inherent limitations of quantitative measures, such as a finite series of questions (Galasinski and Kozłowska, 2010). Furthermore, whilst the impact of the dyadic relationship on the impact of dementia is not fully understood (Braun et al, 2009), it makes sense that research should also include a qualitative approach which enables people with dementia and their carers to offer their truth without the confines of explicit measures. In support, Bourgeois, Schulz and Burgio (1996) emphasise the importance of developing a thorough knowledge and understanding of individuals so that interventions can be developed to a more personal specification.

The following examples demonstrate the importance of first including both partners in research, and also ensuring that the perspective of each individual is not lost. First, Kitwood (1993) found that people with dementia can be passive towards the care they receive from their carer, thus devaluing the importance of their role as a carer. Furthermore, negative or insensitive comments made by carers under stress can be misinterpreted by people with dementia to mean that they are incompetent (Martire, Stephens, Druley and Wojno 2002).

Wuest, King Ericson and Noerager Stern (1994) attempted to improve understanding into couples facing dementia by interviewing carers, and in the majority of these interviews, the person with dementia was also present. The authors used the information gathered to develop a theory of dementia in

couples in which they argued that the ability to hold shared meanings deteriorates eventually resulting in 'Becoming Strangers'. This study is perhaps representative of thinking at the time, and is in contrast to more recent studies which suggest the continuation of feelings of couplehood, as outlined earlier. However, it is an early example of researchers attempting to include the input of the person with dementia in research and the development of a theoretical model.

A further example sees the unusual use of qualitative focus groups during which Marwit, Meuser and Bryer (2005) found that carers demonstrated a greater awareness of the impact of dementia on communication within their marriage, and that the people with dementia focused on more concrete aspects of the impact of dementia, such as their attempts to remain active. This study therefore created themes of communication for carers but was unable to do this for people with dementia because issues of communication were not explored further within that focus group. Therefore, although both partners were included in the research, the outcome of the study was rather carer-orientated.

More recent research has emphasised that theories and models which attempt to explain the impact of dementia on marital relationships, should be developed in terms of a dyadic perspective which takes into account the interactions and impacts between partners with regards to their experiences of dementia (Braun et al 2009).

In an attempt to address the impact of receiving a diagnosis of dementia on a couple, Vernooij-Dassen et al (2006) interviewed eighteen couples (each partner separately) at two weeks and twelve weeks after diagnosis. Three themes were apparent at each time point and represented changes in awareness, changes in their partnership, and changes in social relationships, and an important finding of the study was that although the diagnosis occurred at a specific time point, the assimilation of information and what it meant for the person with dementia and their spouse happened more gradually. Changes in awareness incorporated the feelings of sadness and anger and reflected the

difficulty in coming to terms with the diagnosis in particular because they felt they could no longer live by their own norms. This study offers a further perspective of the impact of dementia on couples because participants were interviewed very soon following diagnosis.

A recent study by Clarke, Keady, Wilkinson, Gibb, Luce, Cook and Williams (2010) combined the perspectives of 55 people with dementia, their family carers and their practitioners in order to establish their views of risk in dementia. This process yielded the identification of what the authors termed 'contested territories', in which the role of dementia across five aspects of everyday life was viewed differently between the three groups. Thus, the authors found evidence of different views with regards to friendship, smoking, going out, domestic arrangements, and occupation and activity. This is a good example of the unique information that can be elicited by including both members of a couple in research because without both of their narratives, researchers would be unaware of the contested nature of the impacts of dementia. Therefore, Clarke et al's study sought to combine the perspectives of people with dementia and their family member and practitioner to ensure that the outcomes were representative of them as a unit. Thus, the result is that research which uses this approach is much more representative of the lived experience for couples because it takes all perspectives into account.

2.4 Conclusion

This chapter has introduced the reader to research into the impact of dementia on people with dementia, their carers and the marital relationship. This has focused on emotions caused by dementia, as well as changes associated with dementia and their impact on individuals and couples. This chapter has identified a gap in the literature with regards to research into the impact of dementia in which both the person with dementia and their spouse are treated as equal partners within the research methodology. Therefore, future research should endeavour to access the subjective accounts of both people with dementia and their carers, and include both partners in research which is ultimately aimed to improve understanding of the lived experience of being a couple facing dementia.

The next chapter will address how people with dementia and their carers cope with the impact of dementia, both as individuals and as couples.

- **Chapter Two** introduced the reader to the impact of dementia on people with dementia, on carers and on the couple relationship.
- With regards to people with dementia, it is clear that they are commonly shocked and upset at hearing the diagnosis. However, the heightened emotions associated with diagnosis do appear to diminish somewhat leaving space for adjustment.
- Negative changes associated with dementia such as increased anxiety, depression and vulnerability may be explained by social implications of dementia or the impact on attachment behaviours. However, more recent research has shown that core aspects of identity in people with dementia endure despite dementia, and that whilst they may experience negative emotions, they are not necessarily the defining features of having dementia.
- Research should endeavour to understand people with dementia's experiences in the context of their lives as this has implications for how the disease is experienced. Recent research has also championed the inclusion of people with dementia in research as well as policy making.
- With regards to carers, caring for a loved one holds two additional challenges compared to other chronic illnesses. The first is attaining and digesting large amounts of information. The second is observing their loved one's deterioration.
- Historically, research has focused on the negative implications of caregiving, including the onset of grief-like emotions in response to losses associated with dementia. However, there is also evidence that caregiving can provide a sense of satisfaction.
- Recent research proposed that the subjective accounts of carers, and investigations into the dyadic components of the carers' experiences, should be prioritised.
- With regards to the couple relationship, it is clear that chronic illnesses impose changes such as those to roles and responsibilities.
- Behavioural changes were more difficult for carers than changes associated with memory. However, while the presence of dementia may initiate some changes in marital relationships, marital decline is not inevitable.
- Recent research has highlighted the need to include both members of a couple in research which aims to understand to experience of dementia within couples. Research which has endeavoured to include both perspectives has unearthed some interesting findings about the differences between people with dementia's and their spouses' experience of dementia.

Chapter 3

Coping with dementia

This chapter focuses on literature related to coping with dementia. In keeping with the structure in Chapter 2, this will be done by first considering coping for people with dementia, then coping for carers, before addressing coping in close relationships. Also in keeping with Chapter 2, research into other chronic illnesses has been included where it helps to illustrate ideas and further understanding into how people cope with chronic illness. The summary of this chapter will present the identification of gaps in the literature, and finally the aims of the present study will be outlined.

Twenty-five years ago, Folkman, Lazarus, Dunkel-Schetter, DeLongis and Gruen (1986) reported that it was generally accepted that there were two primary features that defined the generic understanding of coping. The first regulates the emotions we can experience in response to stressors and the second involves making changes to the person-environment relation that is causing distress. More recently in 2005, DeLongis and Holtzman reported that coping with the impact of stress on health and well-being is generally agreed in the literature to “refer to adaptively changing cognitive and behavioural efforts to manage psychological stress” (p.2). This is reiterated by numerous studies across the field of chronic illness (Matson 1994, Patterson and Garwick 1994). Therefore, the basic understanding of the definition of coping both generically and with reference to chronic illness has not altered much in recent decades. However, attempts to understand how and why coping behaviours are chosen have resulted in conflicting findings.

For example, Folkman et al (1986) attempted to identify what factors may determine the cognitive and/or behavioural strategies that individuals employ during stressful situations and found that differences in coping responses can be attributed, at least in part, to the judgments made regarding what is at stake and the coping options that individuals consider are available to them.

However, caution should be heeded regarding this proposed pathway of judgment influencing coping choice which then influences outcomes. This is mainly due to methodological issues such as the cross-sectional retrospective design of the study, in addition to its sole reliance on self-report measures, and the fact that no attempt at triangulation was made.

Furthermore, there may be other factors which also play a role in determining which coping strategies are used by individuals. For example, DeLongis and Holtzman (2005) proposed that researchers should be mindful of the nature of the stressful event as well as the social context in which it occurred and the personalities of those involved. The authors found that the successful appraisal of the social context in which the stressful situation occurred depended on how well individuals felt supported by those around them. Research into the field of dementia suggests that this could pose difficulties for people with dementia whereby wives of men with dementia were found to be less supportive and facilitative towards their husband than wives whose husbands did not have dementia (Gallagher-Thompson et al 2001).

The exploration of the individual experiences of illness is essential to understanding the potential impact of stressors that individuals and families encounter. This is especially so because while the efficacy of coping strategies can depend on the difficulty of the stressor (Williamson and Schulz, 1993), stressors themselves do not necessarily tell us much about carer outcomes because what is considered to be stressful differs from person to person and/or between social and gender roles (Quayhagen and Quayhagen 1988, Pinguart and Duberstein 2005). In support, Westius et al (2009) proposed that responses to psychological stress are often determined by an emotional predisposition, theoretical assumptions and basic attitude, each of which may contribute to how the individual responds to stress. What is clear though is that the process of making choices regarding the coping strategies employed in response to stress is complex, with a variety of factors possibly affecting the decisions made.

Much discussion within the coping body of literature centres upon comparing the relative benefits of the two most commonly identified types of coping behaviours. **Problem-focused coping** refers to strategies such as information seeking, problem-solving, social support, positive outlook and emotional expression, and **emotion-focused coping** includes strategies such as denial, avoidance, wishful-thinking, suppression and disengagement (Quayhagen and Quayhagen 1988, Stanton et al 2007). Folkman et al (1986) found that emotion-focused strategies were more commonly used when the person saw the encounter as 'unchangeable', whereas problem-focused strategies were more commonly applied to 'changeable' encounters.

The literature in the field of dementia generally supports the suggestion that problem-focused coping in particular is associated with positive outcomes when compared to emotion-focused coping (Quayhagen and Quayhagen 1988, McKee, Whittick, Ballinger, Gilhooly, Gordon, Mutch and Philp 1997, Pakenham 1998, Clare 2002). However, that is not to say that emotion-focused coping does not have an important role in overall coping. Indeed, problem and emotion-focused coping play unique roles in coping whereby emotion-focused coping enables individuals to regulate their stressful emotions, whereas problem-focused coping enables them to make changes to the person or environment which was causing the stress. Therefore, the use of both types of coping may in fact be necessary for successful overall coping (Folkman et al 1986).

In support, Stanton et al (2007) point out that while continual use of emotion focused techniques often leads to maladjustment, they can be of use at certain points when coping with a chronic illness. Certainly, in the field of chronic illness, several studies have reported the benefits of individuals successfully using emotion-focused coping strategies (Coyne, Aldwin and Lazarus 1981, Berg-Weger, McCartland Rubio and Tebb 2001). For example, Aldwin (1994) proposed that emotion-focused coping strategies can be successful when individuals are faced with a stress that involves either harm or loss, which may explain why the use of emotion-focused strategies appears to be adaptive in people facing chronic illness.

Perhaps sensibly, McKee et al (1997) suggest that coping strategies should be merited on their successes per individual as opposed to simply their presentation as problem or emotion focused. Furthermore, researchers should also be aware that the efficacy of strategies may change over time (DeLongis and Holtzman 2005). These points further underscore the importance of learning about the coping strategies employed by individuals and their interpretation of the success or effectiveness of these strategies across situations.

Lyons et al (1995) stated that research into understanding how humans adjust to huge life events makes a valuable contribution. In the absence of a cure for dementia, it is particularly important to explore coping strategies as viable ways to help those affected by the disease. Matson (1994) points out that we assume we know about the most effective ways of coping. However, professionals should be cautious of assumptions and instead be diligent to continue to increase understanding through research. In particular, research that suggests coping strategies can be modified or trained in people (Kahan, Kemp, Staples and Brummelsmith 1985) means that if researchers can determine successful ways of coping then people can potentially be trained to develop them and improve their overall coping ability.

Therefore, coping research in the field of dementia is of the utmost importance for the improved understanding of the experience of dementia which may in turn enable healthcare professionals to develop suitable interventions to help people with dementia and their families to 'live well with dementia' (UK National Dementia Strategy 2009).

The following three parts of this introduction will discuss first research into coping with regards to the person with dementia, then the carers of people with dementia, and finally how relationships play a role in coping with dementia. Research into coping with dementia generally falls into two main areas. The first refers to models that suggest how the experience of dementia develops over time and how this may impact coping, and the second seeks to identify

strategies used for coping. Each of these areas will be discussed within the following three sections.

3.1 Coping in people with dementia

This part of the chapter will outline previous research into how people with dementia attempt to cope with their disease. There will be consideration of the journey that people with dementia tread and how this may improve or impede coping as well as a consideration of the strategies used. The studies included in this part of the chapter focus on coping in people with dementia as individuals.

3.1.1 Process of adjustment for people with dementia

Researchers have made several attempts at charting the experience of dementia for people with the disease. Some of the first researchers to develop a model for coping in people with dementia were Cohen, Kennedy and Eisdorfer (1984) who, following interviews with a large number of people with dementia, identified six stages of adjustment. This began with pre-diagnostic recognition and concern, followed post diagnostic denial, then anger, guilt and sadness, followed by coping, then maturation before finally separation from self. Other researchers have described 'grief-reactions' to dementia such as denial and anger (Kitwood 1997, Bender and Cheston 1997).

Similarly, Keady and Nolan (1994) developed a model of the longitudinal adjustment of people with younger-onset dementia albeit through interviews with 38 *carers* of people with younger-onset dementia. The model consisted of pre-diagnostic stages of 'slipping', 'suspecting', 'covering up' and 'revealing', before diagnosis allows individuals to enter the 'confirming' stage, followed by 'surviving', 'disorganisation', 'decline' and finally 'death'. The surviving stage was later renamed 'maximising' to illustrate that it was dealt with rather more positively by people with dementia than the name 'surviving' suggests. However, as this model was developed following only interviews with carers, further research would be needed to ensure the meaningful involvement of

people with younger-onset dementia in the development of such models which aim to chart their experiences.

Clare (2003) interviewed people with early-stage Alzheimer's disease and their carers separately over two occasions, which arguably addresses some of the methodological criticisms associated with earlier models. This allowed Clare to develop a model of psychological response to dementia regarding the 'threats to self' which included stages of registering the changes, then reacting to the changes, trying to explain the changes, experiencing the emotional impact of the changes and attempting to adjust to the changes. Of particular note with regards to this model is that it recognises that the experience of dementia can be a cyclical process, particularly as people will encounter progressive losses along the way which may require them to return to the initial stage of registering the changes. Clare also recognised that not all people will go through each stage due to individual differences and ways of coping, and this flexibility is useful in a model which is attempting to explain potentially very varied responses to potentially very different experiences for people.

Clare's (2003) model also included a continuum for each of the stages with regards to whether the person with dementia was using self-maintaining strategies or self-adjusting strategies. She argued that self-maintaining strategies, which were primarily concerned with normalising the situation and protecting one's existing sense of self, were less adaptive in the long run compared to self-adjusting strategies, which allowed people with dementia to confront changes and adapt their sense of self accordingly. Therefore, this seems to suggest that seeking a sense of normality (or normalisation as it is termed) may be detrimental to attempts to incorporate changes into one's sense of identity.

However, studies that address how the process of normalisation may be achieved in people facing chronic illness are generally careful to assert that the goal of normalisation is not achieved at the expense of reality. Research into the experience of having a chronic illness found that around the time of diagnosis individuals felt there was little life beyond the problems they were

facing (Robinson 1993), a period which has also been described as one of 'extraordinariness' during which individuals felt alienated, out of control and different to others (Kralik 2002). Following this period, both authors reported that individuals facing chronic illness made attempts to once again achieve and maintain normalisation. This was done by focusing on positive aspects of their situation and minimising difficulties, which was achieved through practical strategies such as routine (Robinson 1993) and receiving appropriate support from loved ones (Kralik 2002). During this time, Robinson also argued that normalisation may prove difficult to achieve because chronic illness can make an individual's situation seem far removed from what they formerly considered 'normal'. In these cases, she argued that people may change how they define 'normal' which may then enable normalisation to be achieved. Thus, people redefine what constitutes 'normal' in line with the progression of their illness.

Furthermore, Kralik (2002) argued that the maintenance of normalisation is only achieved through constant effort, which may be particularly difficult for people with a chronic illness that affects their mental abilities which means that they may be unable to sustain the level of effort required. In both studies, the authors proposed that normalisation is achieved alongside recognition and awareness of the condition. Whether there are any implications for this with regards to people with dementia is not yet known because research into normalisation and dementia so far focuses predominantly on the carer. However, the studies above do provide insight into the importance of normalisation for individuals facing challenges associated with chronic illness.

One feature that transcends all of these models is the idea of reaching a resolution that is represented by a balance between hope and despair (Clare 2002) the benefit of which is linked to the implementation of successful coping strategies (Cohen et al 1984). Different semantics are used to refer to this balance such as 'acceptance' (Cohen et al 1984, Kitwood 1997, Clare 2002) 'maximising' (Keady and Nolan 1995), oscillation between acceptance and anger (O'Shaughnessy et al 2010) and achieving a sense of normality (Robinson 1993, Kralik 2002, Brown and Roch 2010), but all advocate this as the overall aim for people with chronic illness.

3.1.2 Strategies used by people with dementia

In addition to models that attempt to describe the chronological process and experience of coping with dementia, other research has focused on the specific coping strategies used by people with dementia and found successful coping may be achieved using strategies that were traditionally considered to be maladaptive or at best less effective (Bahro, Silber and Sunderland 1995). To illustrate this further, Bender and Cheston (1997) discussed the common psychological responses made by people with dementia in response to the deterioration of the disease, and argued that although outwardly negative, denial, living in the past, attachment, apathy and withdrawal may all play important roles in the overall adaptive process for people with dementia. Thus, dementia poses unique challenges for people with the disease, which can require unique methods of coping.

When compared to people with other chronic illnesses, there exists much less research into the direct experiences of people with dementia. However, this is beginning to change with research that has been undertaken showing that people with dementia certainly make active attempts to adjust to and cope with their situation (Bender and Cheston 1997, Woods 2001, Clare 2002, de Boer et al 2007). Studies into the experience of dementia and how people with the disease try to cope with it also acknowledge the presence and value of both problem-focused and emotion-focused coping strategies (de Boer et al 2007). For example, Keady and Nolan (1995a) developed an index (Index for Managing Memory Loss: IMMEL) which included 42 coping strategies described by people with early stage dementia such as “Being open and honest about my memory loss with people that I meet” and “Establishing a regular routine and sticking to it” (p.311). Keady and Nolan argued that all of the strategies they identified came under one of the three ways in which Nolan, Grant, Caldock and Keady (1994) suggested coping operates. These were taking direct action, which could be seen as problem-focused coping, and developing alternative perceptions and managing the symptoms of stress by

relaxation techniques, both of which arguably constitute emotion-focused coping.

Furthermore, in her model of psychological response to dementia, Clare (2002) argued that the stages of recognising changes, reacting to them, explaining them and adjusting to them are linked to different sets of coping strategies that help the individual to master each stage and move on to the next. She proposed that strategies that hold on to previous abilities are utilised first, before those that focus on compensating for losses are used. Finally the development of a fighting spirit allows individuals to move towards successful coping and acceptance.

There is also evidence regarding the efficacy of individual strategies. For example, problem-focused strategies, and in particular those that enable the person with dementia to complete activities of daily living independently, have positive implications for the individual's sense of mastery (Cohen et al 1984) and overall quality of life (Keady and Nolan 1995b, Andersen, Wittrup-Jensen, Lolk, Andersen and Kragh-Sorensen 2004). The use of emotion-focused strategies is also well represented in the literature regarding people with dementia, such as denial (Bahro et al 1995, Bender and Cheston 1997). Due to the unique challenges facing people with dementia, Ingebretsen and Solem (1992) argued that dementia calls for flexible coping strategies in order for people with dementia to cope appropriately as things change. However, research findings can be contradictory in that on the one hand they suggest that a degree of flexibility is required and on the other they advocate forming and sticking to strict routines, which arguably fosters conflicting attitudes. Indeed, it may not be realistic to expect people with dementia to manage a flexible attitude towards coping with dementia particularly considering the inevitable decline in reasoning and communication skills.

Indeed, there are further idiosyncrasies regarding people with dementia, for example, around the notion of awareness. Whilst good awareness is generally regarded to form the basis of many adaptive coping strategies, Bender and Cheston (1997) warn that awareness among people with dementia can be

problematic if it leads to terror at the thought of what lies ahead. Conversely, they also argue that a lack of awareness may lead the person with dementia to foster unrealistic expectations of their ability. Therefore, it is important that research attempts to understand coping with dementia on an individual basis if we are to further understand what constitutes good coping strategies and the factors that underpin the success of those strategies.

Taking this approach into account, the recently developed qualitative method of 'Co-constructed Inquiry' not only aids the understanding of the impact of dementia but also concentrates on furthering understanding around how people with dementia adapt to their disease in the context of their life experiences (Keady et al 2007). The authors argue that by identifying the 'supporting struts' that have been essential to the success of coping efforts throughout the person with dementia's life, this provides healthcare professionals with a starting point regarding suitable interventions for each individual. Thus, future research should endeavour to access a more individualised approach to understanding experiences of dementia to enable findings to be used in the development of interventions which are sympathetic towards individualised responses to dementia.

3.2 Coping in carers

This part of the chapter will outline previous research into how carers of people with dementia attempt to cope with their loved one's disease. There will be consideration of the journey taken by carers and how this may improve or impede coping as well as a consideration of the strategies used. The studies included in this part of the chapter focus on carers coping as individuals. Coping in close relationships will be addressed in the final part of this chapter.

The experiences and coping efforts of carers of people with dementia have received much more attention in research, due primarily to the fact that there are far fewer methodological obstacles compared to research with people with dementia (as outlined in Chapter 3). However, what is common across people with dementia and carers is that there are wide variances with regards to

responses to dementia. Lyons et al (1995) proposed that this variance may somewhat be affected by the characteristics of the condition and the psychological characteristics of each individual as well as current or pre-existing characteristics of close relationships.

Again in line with people with dementia, research has also found that carers of people with dementia face unique challenges due to the nature of the disease, and as such, research has uncovered some perhaps unexpected findings. For example, although the 'impact' chapter illustrated that often long term caring is represented in a negative light e.g. risk of burnout (Almberg et al 1997), there is also evidence that coping with the caring role can improve over time (Gilhooly 1984) perhaps reflecting that carers benefit from time to develop successful context dependent coping strategies in response to the issues they have faced (McKee et al 1997). Therefore, whilst research may know relatively more about carers' responses to dementia, efforts should continue to endeavour to understand the variance that occurs for carers (Zarit et al, 1998).

3.2.1 Process of adjustment for carers

Several models have been developed which focus on the experience and coping efforts of carers for people with dementia, with different focuses such as identification of different types of carer or explaining the practical and emotional journey carers undergo. These models therefore, also offer some insight into the variance among responses of carers. For example, Ingebretsen and Solem (1998) attributed the differences between boundary setting carers and those who became overwhelmed or over-involved with their caring role, to whether the carer was securely or insecurely attached to their spouse. While this study referred to spouse carers, perceived divisions between the new role of a carer and the existing role for family members or friends may also occur.

A number of models have been developed that suggest that carers may proceed through a number of stages while attempting to come to terms with their loved one's dementia. Nolan et al (1996a) developed a model that encompassed carer reactions from pre-diagnosis to post-death of the person

with dementia. This model is similar to those described for people with dementia in that it begins with 'building on the past', then 'recognising the need', followed by 'taking it on', and 'working through it' (which is similar to the 'acceptance' stages in people with dementia models), before 'reaching the end' and adjusting to a 'new beginning'.

In a single case study of a husband carer, Galvin, Todres and Richardson (2005) conducted a series of interviews with the carer through which they gained longitudinal understanding of the lived experience of dementia. Similarly to other models, this started with the recognition that 'something was wrong'. This was followed by 'the challenging shared journey: being the carer' during which the authors found the carer was managing competing aims such as taking care of both his wife and himself. The final stage represented his wife's move into a care home during which time the carer became her advocator, forging links with appropriate professionals and agencies in order to ensure her the best possible care. This model was later expanded to six stages which represented the journey of the carer during the case study. They were 'learning to live with the loved one's memory loss', 'adjusting to more limited horizons in their life together', 'caring in practical ways', 'adjusting to changes in the emotional relationship and level of intimacy', 'the transition of living apart' and finally 'advocating on the loved one's behalf' (Todres and Galvin 2006). The authors recognised a decline in reciprocity as the person with dementia became less able to contribute to the relationship. However, the benefits of simply 'being' with each other, during which the 'cared-for/carers' relationship was allowed to slip away at least for a time, were emphasised by the authors. Recapturing the essence of their relationship allowed this couple a chance to reconnect following their initial responses to dementia which were understandably characterised by anger and frustration.

A further model of caregiving by Perry (2002) was developed through interviews with wife carers of husbands with Alzheimer's disease. She proposed that carers go through a process of 'Interpretive Caring' during which they first 'recognised' the changes in their husbands, then 'drew inferences' about why this was happening. Following this, Perry predicts a period where

the wives 'take on' roles and responsibilities previously owned by their husband, which then lead to wives 'rewriting their husband's identities' which allowed them finally to 'construct a new daily life' in which the wives ensured that their husbands continued to play a role as their abilities allowed. This model recognises that spouse carers have access to a cognitive dimension of caring, because the in-depth knowledge they have of their spouse allows them to make valid interpretations of their loved one's behaviour. Thus, this model suggests that a reconnection (as above) is afforded to carers who are able to redefine their spouse's identity and their daily lives. Furthermore, this model also recognises that the role of a carer can be perceived negatively or positively, and that in most cases, carers will have both positive and negative experiences, often simultaneously. This is important because it accepts the challenges associated with dementia but also recognises carers' strengths with regards to their responses to these challenges.

However, Perry's model was developed solely with wife carers, which means that the results may not necessarily be translated directly to husband carers. Indeed, gender differences in response to symptoms of Alzheimer's disease were reported by Hayes, Zimmerman and Boylstein (2010) who found that although wife carers recognised the changes in their husbands, as found by Perry, the authors also found that wives were sometimes reluctant to discuss their concerns with their husbands, perhaps in order to protect their sense of masculine identity. Furthermore, these authors found that husband carers were slower to identify that the changes they had observed in their wives were attributable to dementia (also Kirsi, Hervonen and Jylha 2004), and usually it was someone else that brought the problems to the husband's attention. However, despite this, husband carers seemed better able than wife carers to normalise the situation. The authors explained this finding by proposing that the impact of dementia may be less disruptive to marital dynamics, and in particular authority relations, for husband carers than wife carers. Therefore, researchers should be aware of the potential for gender differences with regards to the impact of dementia as well as how carers respond to these issues.

These models suggest that carers undergo certain adjustments or experience certain emotions, but what might be the motivation behind these adjustments and emotions? The following paragraphs will outline how the grieving process has been linked to caregiving in dementia and how this may help to explain the occurrence of particular emotions, before moving on to address how the need to achieve normalisation may explain the observations made in the models above.

Grieving is generally represented in the literature by the existence of stages through which individuals work after they have suffered bereavement or other substantial loss. These stages are denial, anger, depression, acceptance and reconstruction, which displays some likeness to the stage models outlined above which pertain directly to the experience of dementia. Indeed, researchers have made this link (Kitwood 1997, Todres and Galvin 2006, Ott et al 2007) and demonstrated that the grieving process can also be experienced in response to dementia. As such it could be argued that time of diagnosis, like death, can represent a point in time after which grieving commences. However, thinking of grieving and dementia linearly does have its limitations, for whilst time of death and time of diagnosis both represent one point in time where loss is confirmed, for the carer of someone who has died, this concept is more straight-forward: that person is no longer alive, and for their spouse, there is a definite point whereby grieving can begin. However, for someone whose spouse has just been diagnosed with dementia, that diagnosis can be perceived as the beginning of a journey during which they will slowly and cruelly lose their spouse. Therefore, while carers of people with dementia experience losses over which they no doubt feel grief (Ingebreetsen and Solem 1998), they do so in a slightly different way to the traditional grief model associated with death due to the degenerative nature of dementia and the associated losses (Ott et al 2007). For example, grieving over the loss of intimacy in the relationship and feelings of grief around the need to redefine aspirations for retirement (Todres and Galvin 2006) might also be experienced. However, Perry (2002) outlined that whilst carers may grieve for their spouse, this does not necessarily permeate the whole experience of being a carer.

Indeed, Perry argues that positive coping strategies are often used despite the presence of negative emotions.

A further theory which attempts to explain the responses made by carers is the theory of normalisation which was developed by Clarke (1999) for carers of people with dementia. Clarke argued that coping with dementia spans three levels of first normalisation, then interfacing, and finally interacting. Interfacing constitutes decisions about the nature and extent of professional involvement, and interacting represents the final stage where the person with dementia, their family and the professional carers work together, but it is the first stage of normalisation that is most pertinent to people facing mild dementia. Clarke proposed that normalisation is achieved by carers through establishing caregiving, negotiating factors that affect it, and developing strategies that help with it.

The first phase of 'establishing caregiving' is influenced by the past life of the person with dementia and their carer as well as by their expectations regarding homecare. The second phase acknowledges that there are factors which may affect the efficacy of normalisation such as whether there is perceived reciprocity within a couple, whether the implications of dementia had contributed to a loss of self-identity, and whether carers had adjusted well to dementia. The third phase identifies strategies that were conducive to the development of normalisation for carers. One strategy called 'pacing', referred to carers limiting the physical and emotional exposure to their spouse perhaps through respite care. A further strategy called 'confiding' referred to the use of social support in order to identify problems and discuss their solution. A final strategy referred to whether changes were attributed to the person with dementia or to the dementia itself.

The theory predicts that health professionals either try maintenance activities that prolong family carers ability to continue caring, or they encourage 'movement' whereby they focus the family on the disease as an aid to accepting services as necessary. The latter may become more pertinent for people facing moderate to severe stages of dementia where professional input

is required more and more as family carers experience more frequent and severe symptoms of the disease. However, in order to successfully adapt to the experiences associated with the second and third stages of this model, it seems important for families to have gained some level of normalisation because being able to normalise may mean that the integration of professional services may be done with minimal disruption to the carer or person with dementia.

The models presented here have illustrated how the experience of caring for someone with dementia has been explained in the literature to date. These models have focused on the experience for carers as individuals and how they independently attempt to cope. However, recent research still calls for further qualitative research regarding the experiences of carers and in particular how these experiences are constructed by carers (O'Shaughnessy et al 2010). The following section will detail the specific strategies that have been identified for use by carers.

3.2.2 Strategies used by carers

Traditionally, problem-focused strategies were considered to be psychologically healthy while emotion-focused strategies were thought to encourage rumination and ultimately be unhelpful for coping (Almberg et al 1997). However, it is now well accepted in the literature that successfully coping with caring for someone with dementia requires the use of problem and emotion-focused coping strategies, the latter of which may help carers to come to terms with the degenerative nature of the disease (Matson 1994, Almberg et al 1997, Epping-Jordan, Compas, Osowiecki, Oppedisano, Gerhardt, Primo and Krag 1999). These strategies have been briefly mentioned earlier in the thesis. This section focuses on strategies reported for carers.

Problem-focused strategies include confronting the problem (Almberg et al, 1997), seeking information (Almberg et al, 1997, Stanton et al 2007), seeking social support (Morrissey, Becker and Rubert 1990, Quayhagen and Quayhagen 1998, Almberg et al, 1997, Stanton et al 2007, Charlesworth,

Tzimoula, Higgs and Poland 2007), problem-solving (Quayhagen and Quayhagen 1998, Szabo and Strang 1999, Stanton et al 2007), ability to recognise their own needs, (Szabo and Strang 1999) and attempting to identify benefit in the experience (Stanton et al 2007).

Whereas these strategies were considered to be adaptive due to their inclusion under the 'problem-focused strategies' umbrella, their value for carers facing dementia is not always agreed upon in the literature. For example, with regards to seeking information about the disease, Proctor, Martin and Hewison (2002) found that carers who sought more information were at more risk for stress than those who did not. Similarly, Graham, Ballard and Sham (1997) found that carers with higher knowledge exhibited more anxiety than those with less knowledge. This may be explained by the fact that increased awareness of the disease may result in increased anticipation of loss. However, carers with higher knowledge also reported lower rates of depression, were more confident and held lower (more realistic) expectations for their spouse. This led the authors to conclude that more information could actually help prevent depression in carers. Therefore, further research is needed to investigate further the role of knowledge for carers and whether it acts as a help or hindrance to their coping efforts.

Emotion-focused strategies include wishful thinking/fantasy (Quayhagen and Quayhagen 1998, Almberg et al, 1997, Ingebretsen and Solem 2002, Matson 1994), stoicism (Almberg et al, 1997), grieving (Almberg et al, 1997), worrying (Almberg et al, 1997), self-accusation/blame (Almberg et al 1997, Quayhagen and Quayhagen 1998), acceptance (Almberg et al, 1997), denial/avoidance (Ingebretsen and Solem 2002, Matson 1994, Stanton et al 2007), passivity (Matson 1994), suppression (Stanton et al 2007), use of confident language (Szabo and Strang 1999), disengagement (Stanton et al 2007), personal growth (Berg-Weger et al 2001, Ott et al 2007) and reframing the situation, achieving a sense of competence, family loyalty, discovery of inner strength, sense of purpose, personal growth and sense of importance (Berg-Weger et al 2001).

Emotion-focused strategies may help carers to process what their loved one's dementia means to them (Matson 1994). Part of this process involves diagnosis, and rather than being necessarily a negative event, some research suggests that it can be positive for carers as it explains the changes they have observed (Baikie, 2002) and may also help to diminish feelings of blame. In support, Cooper, Katona, Orrell and Livingston (2008) found that the use of emotion-focused strategies seemed to protect carers from increasing levels of anxiety a year later. This was in contrast to problem-focused strategies whose use did not appear to protect carers from anxiety. This underscores the importance of emotion-focused strategies for carers coping with dementia.

Furthermore, several of the emotion-focused strategies listed above promote positive attitudes towards dementia, which is testament to their value for carers coping with dementia. For example, Ott et al (2007) found that the majority of carers in their study reported personal growth as a result of their caring experience. Therefore, although dementia produces challenges in terms of grieving for losses and everyday life, the experience of caring for a loved one with dementia can also foster a sense of personal growth for the carers. Perhaps the presence of positive emotions is necessary in order for carers to access important emotion-focused strategies such as achieving a sense of competence or discovering inner strength. Indeed, carers' own appraisals of their situation appear to have an effect on their stress levels and psychological well-being, meaning that viewing their caring role positively could potentially improve their experience of being a carer (Berg-Weger et al 2001, Cousins, Davies, Turnbull and Playfer, 2002 – all dementia).

Conversely, McKee et al (1997) found that most carers in their sample used non-confrontive emotion-focused strategies, which included passivity, avoidance and wishful thinking. This is in contrast to the other studies above which identified the use of more positive emotion-focused strategies. However, the fact that some studies have found predominant use of non-confrontive strategies suggests that they might perform some service to carers. Indeed, even those emotion-focused strategies traditionally believed to be counter-productive could be adaptive when used at certain points by individuals caring

for someone with dementia (Bender and Cheston 1997). For example, Matson (1994) found that over a six month period, and in response to increased dependency from the person with dementia, carers used fewer problem-focused strategies and increased 'non-confrontive' strategies. Therefore, perhaps the use of these strategies is done so in response to events, although unfortunately this study did not continue to review the carers, so it is unclear whether coping strategies altered again in the future. It should be noted here that there is a decided lack of longitudinal work in the field of coping in dementia generally, and future research should endeavour to redress this balance. This would help illuminate how events shape the immediate and long term use of coping strategies and longitudinal studies are better placed to provide insight into what may cause the use of different coping strategies.

3.3 Coping in relationships

Statistics show that two thirds of people with dementia live in the community (Alzheimer's Society 2007) where they are often supported by relatives and friends. By recognising that carers may be required to provide care seven days per week, this illustrates the potential importance of the relationship between the person with dementia and their carer, a link which has been made frequently in the literature (Gilhooly 1986, Morris, Morris and Britton 1988, Coyne and Smith 1991, Wright 1993, Lewis 1998, Montgomery 1996, Blanchard et al, 1997, Knop, Bergman-Evans and Wharton McCabe 1998, Sormanti and Kayser, 2000, Baikie 2002, Hellstrom, Nolan and Lundt 2005, Quinn et al 2009).

The importance of relationships was clearly outlined by Lyons et al (1995, p1) who said that "serious health problems challenge the quality and maintenance of relationships with family and friends at the same time that such relationships play a pivotal role in coping with illness". It is therefore important for research to investigate the coping strategies employed by all people affected by chronic illnesses as well as their subsequent adjustment to their illness. This knowledge will also help health professionals: 'by identifying variables that are linked with different levels of individual and family functioning in families who

exhibit different patterns of response to illness, we will be better positioned to develop and test interventions that address the unique needs of families.’ (Knafl and Gilliss 2002, p192). Thus, although researchers agreed that close relationships were important in dementia less research attention has been directed towards this issue.

3.3.1 Process of adjustment for couples

This chapter has already presented models that describe and explain the process of adjustment for people with dementia and their carers as individuals. As research has continued to emphasise the importance of close relationships, a number of models have also been developed that focus on how people with dementia and their carers cope as part of a couple.

One of the first models addressed the ‘changing family caregiving relationship in Alzheimer’s disease’ (Wuest et al 1994). This model called ‘Becoming strangers’ was developed following interviews with carers, which sometimes included the person with dementia. It is a cyclical model of adjustment which takes into account the changes and deterioration caused by dementia, and therefore reminds us that preferential and efficacious coping methods may change according to the stage of disease or adjustment. The authors propose that couples inevitably progress from intimacy to alienation, via three stages of ‘dawning’, ‘holding on’ and ‘letting go’. They also recognised that the stages involved in this process often overlapped and as such did not propose that the stages were clear cut. The initial stage ‘dawning’ consisted of carers and people with dementia attempting to explain the changes in the person with dementia’s behaviour, whilst attempting to maintain at least the appearance of normality until the carers realised that the changes observed in their loved one could no longer be dismissed. In the second stage, ‘holding on’, the authors proposed that carers devise strategies that help to maintain a good relationship with their loved one as well as an acceptable quality of life for them both. This is achieved, they predict, by carers gaining control (through the development of routines), gaining knowledge and creating meaning. The third stage of ‘letting go’ is reached when the carer can no longer meet the

demands of their loved one's dementia and is forced to consider institutionalisation.

This model made some attempt to understand how relationships adjust to dementia and recognised that commitment between spouses affects progression through these stages, also found more recently by Daniels et al (2007). However, it also fails to fully acknowledge the role of the person with dementia. Indeed, people with dementia were not referred to specifically in the model after the initial stage of 'dawning'. In a model that seeks to represent how couples 'become strangers' it is a shame that the views of the people with dementia were either not sought or not used to further enrich the details of at least stage two ('holding on') whereby arguably both people with dementia and their carers play active roles in the development and maintenance of strategies. Furthermore, research has shown that people with mild to moderate dementia were able to provide reliable answers regarding their quality of life (Trigg, Jones and Skevington 2007).

Again, with reference to carers, Sandberg and Eriksson (2007) found that the three Swedish male carers they interviewed described 'taking on new and unfamiliar roles' and 'learning to live with them'. This is arguably similar to other stage models of adjustment in dementia in that they all describe an element of adjustment to change. However, this study provides further insight into how the changes were experienced by carers and the effect this may have on their relationship. Indeed, this study showed that carers attempted to maintain continuity in their relationships with their wives, primarily through the use of practical goal orientated coping strategies such as helping with washing and dressing. They argued that this enabled their wives to keep to a schedule that most represented 'normal life', which the male carers said helped to keep them sane. Although these findings are not generalisable due to the small sample, the importance of routine and gaining control was also identified in Wuest et al's (1994) model. However, research should also endeavour to determine what role people with dementia play in this process by including them directly in research.

To illustrate this further, Daniels et al (2007) interviewed one couple in which the wife had dementia, on three occasions over a six month period. This longitudinal method allowed the researchers more in-depth access into a couple's perspectives, which helped to enhance understanding of the overall experience of dementia. For example, the authors identified four key themes, only one of which was exclusively centred upon experiences associated with dementia. The remaining three themes comprised preparing for the future, recognising the influence of family and social support, and engaging in life evaluation. These three themes were represented generally in their relationship as well as in response to dementia, and allowed them to assess the impact of dementia and cope with this impact by understanding why it was occurring and being able to attribute problematic behaviours or mishaps to the dementia. The ability to find meaning and joy was also important. This study illustrates how including both the person with dementia and their spouse in research, particularly by way of qualitative methods, allows researchers to access rich data relevant to that couple.

A further longitudinal study into how relationships are affected by dementia was conducted by Hellstrom, Nolan and Lundh (2007). This study led to the development of a model for progression for couples facing dementia, through interviews with twenty couples. The authors reported that couples were at first interviewed individually but by the end of the data collection period, more interviews were conducted together. Unfortunately, it is not clear why this changed, and whether this was in response to preferences from people with dementia and/or their carers or whether it was an analysis-orientated decision. The model itself focuses on the period following diagnosis, and the first stage 'sustaining couplehood' involves talking things through, being affectionate and making the best of things. The second phase focuses on 'maintaining involvement' of the person with dementia. The authors propose that the first two phases can operate simultaneously. The importance of maintaining involvement of the person with dementia was also identified by Keady (1999) who considered it a crucial part of the caring relationship. Finally, as the first two phases begin to fail, the final phase of 'moving on' comes into play. During moving on, couples may either stay as a 'we' or carers report a move to

'I'. A further sub-theme of 'new beginnings' was also reported by carers who had experienced their spouse moving into nursing care or the death of their spouse.

The stages of 'moving on' or 'letting go' represented in these models are thought to be important because they help carers to accept the inevitable, which in turn enables them to develop suitable coping strategies (LoboPrabhu, Molinari, Arlinghaus, Barr and Lomax 2005). LoboPrabhu et al also point out that researchers should be aware that long-standing values surrounding marriage and commitment may serve to encourage the upholding of the caring role, and as such, the role of relationships in dementia deserves more attention.

Certainly, research is starting to see a move towards the meaningful inclusion of people with dementia in research, and this is particularly useful in studies that investigate close relationships in dementia. Comparing all of the models presented thus far, it is clear that they all incorporate features of recognition of dementia and its challenges and that people with dementia and their carers adapt to change. However, models that seek to explore the experience of couples afford researchers further access to the motivations behind the recognition, understanding and use of coping strategies within the context of a spousal relationship. It is for future research to further this understanding.

For example, the theory of normalisation was previously presented in this chapter both with regards to people with dementia and their carers, but there is a lack of research into how normalisation may be developed, maintained and affected by close relationships in dementia. Research has shown that the presence of a chronic illness in general, especially one where the course of the illness is uncertain and progressive, may make the process of normalisation more challenging (Robinson 1993, Patterson and Garwick 1994, Clarke 1999, Knafl and Gilliss 2002). Furthermore, research into chronic illnesses has emphasised the importance of close relationships in achieving normalisation (Robinson 1993, Kralik 2002). For example, Patterson and Garwick (1994) proposed that families achieve balanced functioning by focusing on the family

as a whole and balancing the needs of the ill person with the needs of other family members. As such, it is important to be aware that family interactions could influence the 'course' of the illness as well as considering the 'impact' of the illness on the family (Steinglass and Horan, 1987). Therefore, whilst normalisation does appear to play an important role for close relationships in the adjustment to chronic illness, future research should attempt to investigate the role of normalisation in couples where one partner has dementia.

This section has introduced a number of models that have been developed with regards to overall adjustment for couples in which one partner has dementia. This has shown that over time researchers have more commonly included the person with dementia as an equal party in research. This has provided a richer understanding of the experiences of couples as well as insight into how people with dementia and carers adjust but within the context of their spousal relationship.

3.3.2 Key features of couples coping with dementia

Research into couples facing dementia also includes work regarding more specific areas of their experience and coping strategies. As such, four key areas can be identified that include existing research but also need further understanding: awareness, mutuality, communication and relationship-focused coping. Each will now be addressed in turn.

3.3.2.1 Awareness

Within the field of dementia, there is limited understanding as to how awareness is constructed within couples. Hellstrom et al (2005) attempted to address this in a qualitative study with 20 couples facing dementia. They found that awareness represented a shared view of the world, and more specifically their situation, which was negotiated between each couple. The authors referred to Awareness Context Theory (ACT) as a theoretical way of understanding the construction of awareness among couples which argues that shared awareness within couples is attained through knowledge of the

illness and an agreement about what it means for them. They found that awareness in dementia was related to awareness of memory difficulties and associated problems, awareness of how these difficulties might develop in the future, and awareness of the impact of memory problems on their partner. As such, it was revealed that being 'aware' of the diagnosis is a only small part of the bigger picture in which people with dementia and their partners developed a shared view of what the diagnosis meant for them and what impact it had on their lives. Furthermore, the presence of a shared awareness about the prognosis of the disease did not always lead to couples using confrontive methods of coping. A number of couples, whilst aware of the prognosis, actively chose to focus on the present as they felt they did not want to worry about the future while the person with dementia was still fairly high functioning.

If (as this theory suggests) knowledge of the illness is crucial to the development of a shared view, does this mean that shared awareness would be compromised as the person with dementia becomes less and less able to comprehend the knowledge about their illness? The authors give examples which seem to suggest that as the person with dementia deteriorates it becomes increasingly difficult for couples to maintain a shared view and agreement about the illness and its impact on their lives. This was often linked to a lack of awareness regarding the impact of dementia on their partner. Indeed, the successful construction of awareness was heavily related to the awareness of the impact of dementia on the carer. The authors propose that where couples do not attempt to develop shared views, they will ultimately drift apart with each member of the couple dealing with the illness independently. However, it must also be remembered that awareness is not only developed in agreement with one's partner. Each partner must also seek to understand and assimilate dementia into their lives in a way which makes sense to them as individuals as well as part of a couple. This study provided some interesting insights into how awareness is developed within couples, and how developing shared awareness within couples may allow them to develop a shared approach to dementia. However, further research is needed into the role of awareness for couples facing dementia, and in particular with regards to the extent to which it affects the use and efficacy of coping strategies. Indeed,

Cooper et al (2008) proposed that successful coping for carers in dementia may hinge upon their ability to use problem-focused strategies when situations can be changed, but also to use emotion-focused strategies when the situation cannot be changed. However, more research is needed into how awareness regarding the changeability of situations may impact on the use of coping strategies.

3.3.2.2 Mutuality

Gallagher-Thompson et al (2001) proposed that the concept of mutuality encapsulates “several aspects of marital satisfaction, including reciprocity in the relationship, feelings of closeness, and shared values and everyday pleasures.” (p.S142). Moreover, researchers have emphasised the importance of a sense of mutuality (Sormanti and Kayser 2000) and empathy (DeLongis and O’Brien 1990) between spouses in order to cope successfully with illness.

The key feature of mutuality that may be compromised in couples facing dementia is reciprocity, which is the idea that each partner contributes in a meaningful way to the relationship. Several of the models so far presented have discussed the importance of ‘balance’ in dementia (Patterson and Garwick 1994, Clare 2002). Indeed, where overall balance is disrupted within relationships, Equity theory predicts the eventual breakdown of these relationships (Walster et al 1978b). In support, Neufeld and Harrison (1998) predicted that the presence of dementia and its associated demands for the carer can render a relationship unreciprocal, and de Vugt (2003) found that carers who reported a lack of reciprocity with their spouse, also reported a higher level of relationship change overall.

However, this is not always the case, and a good number of couples continue to stay together despite the apparently unreciprocal nature of their relationships, which do not, as Equity theory suggests, break down (LoboPrabhu et al 2005, Mann and Dieppe 2006, Daniels et al 2007, Sandberg and Eriksson 2007, Hellstrom et al 2007). Perhaps Equity theory does not take love or obligation into account. It may be argued that couples are prepared to

endure difficulties along the way. Inherently, they agree to marry 'for better or for worse' and people are usually aware that partnerships which span many years will encounter ups and downs (LoboPrabhu et al 2005).

A further explanation as to why seemingly non-reciprocal relationships endure is 'lifespan reciprocity', in which the carer views the care that they provide for their spouse in terms of the care their spouse has given them over the years (Lewis 1998, Sandberg and Eriksson 2007). Therefore, this illustrates that immediate reciprocity in a relationship is not necessary if a long term sense of balance exists, as often does in marriages and parent-child relationships (Lyons et al 1995).

A further example of how reciprocity and therefore mutuality can be maintained in couples facing dementia was developed by Lewis (1998). She proposed that each partner may potentially act as caregiver in some capacity which enables couples to share 'complimentary' disabilities. For example, the person with dementia may help their spouse with a physical difficulty while their spouse helps the person with dementia to remember the way to the shops. This may be unsustainable for the full duration of dementia, but it is an interesting concept for people in the mild to moderate stages of dementia. Future research should concentrate on accessing both partners' views of this concept, and further investigate its utility for improving feelings of reciprocity and mutuality in relationships.

This idea of spouses working together has often featured in research into couples facing dementia. For example, Keady and Nolan (2003) identified four types of working relationships between couples where one has dementia. First, 'working alone' whereby one partner works in isolation from the other. Second, 'working separately' represents each partner working in parallel but separately. This usually occurs around the time the person with dementia may be trying to cover up their mistakes and their carer may be trying to confirm their suspicions that something are wrong, or vice versa. Thirdly, 'working together' refers to couples who are open about their feelings and who work together to make the best of things. Lastly, 'working apart' is utilised within relationships

whereby both partners find it difficult to mutually agree on the way forward, perhaps due to poor existing relationship. Furthermore, Hellstrom et al (2005) reported that working together was a key feature of successful coping in couples facing dementia. Also central to successfully working together was the ability for couples to recognise the roles that they held and the ways in which they were complimentary to one another. The authors referred to the importance of 'Nurturative Relational Context' in which couples actively manage the ways in which they live with dementia.

The idea of working together was also reported with regards to couples facing rheumatoid arthritis. Mann and Dieppe (2006) interviewed twelve couples and found that the ways in which they thought about the illness as a couple had an impact on how well they coped with the impact of the illness. They defined three groups: the first group involved couples who shared the management of the illness by referring to it as 'we/our' and both individuals were pleased with the way in which the other was coping. The second group saw the ill partner in charge of the illness, often defined by the ill person attending appointments alone. In this group, the well partner focused on the effort seemingly being put in by their ill partner, which sometimes caused conflict. In the final group, conflict existed over the management of the illness and often the well partner was critical of the way in which their partner was coping. Approval from each partner, and who had the prerogative to decide on the illness management strategy were both strong components of whether they felt they had achieved satisfactory coping as a couple.

Therefore, the way in which couples approach dementia (and other chronic illnesses), and the affect on feelings of reciprocity, may influence overall feelings of mutuality within spousal relationships. However, this research has not illustrated why some couples feel reciprocal while others don't, or why some work together or share management of the illness, whereas other couples experience different ways of approaching and coping with dementia. Clearly then, there is scope for further work in this area.

3.3.2.3 Communication

Several studies have reported that meaningful communication within close relationships in dementia and other chronic illnesses can be difficult for those involved (Rees, Bath and Lloyd-Williams 1998, Keady and Nolan 1995b, Pistrang, Clare and Baker 1999) for reasons such as not wanting to upset their spouse (Hellstrom et al 2005). However, effective communication has also been linked positively with coping (Vess, Moreland and Schwebel 1985).

For example, Roberto, Richter, Bottenberg and Campbell (1998) defined three types of communication patterns between spouses when one of them has dementia. 'Parallel' involved conversation between both partners, 'Continual Questioning' was usually carried out by the well spouse and often without waiting for a response from the person with dementia. Finally, 'Repetitive Speech' was used by either the person with dementia or their spouse. The authors suggest that pre-existing communication patterns are exaggerated by dementia. However, couples may respond to advice about ways to improve communication such as repeating questions, allowing time for response and reducing ambiguity.

Furthermore, Marwit et al (2005) suggested that it is important that good communication practices are established and discussions concerning important issues are conducted, during the early stages of the disease. These authors developed a model of communication in couples facing dementia which was based on Awareness Context Theory, and follows the chronological process of adjustment starting from when they suspected something was happening. The categories began with 'closed' which represents no communication or apparent recognition of the problem. Next, 'suspected' describes the use of questioning and withholding with the person with dementia suspecting more than they know, and their carer knowing more than they disclose. Next, some couples demonstrate 'mutual pretence' whereby there is no communication on the matter and couples continue to interact as if nothing is wrong. In this case, both partners are thought to have partial to full awareness that they are avoiding the subject. The next stage marks a move

towards more adaptive modes of communication whereby 'benevolent' refers to couples whose communication is limited to safe topics that are less likely to upset. The person with dementia is thought to be minimally or partially aware of this while their carer is thought to know more than they disclose because they wish to protect their spouse from any harm or upset. Couples may also experience 'limited open' whereby both spouses are aware of the problem but one is more willing to discuss it openly than the other. In this case, both partners are partially to fully aware but communication is again often restricted (usually by the carer) to safe topics. Finally, 'open' communication sees candid discussion between partners. The authors suggest that this final stage is the most adaptive; although researchers should be cautious about how often couples reach this stage. Marwit et al found that the people with dementia often saw the communication within their relationship as being 'open', while the carers acknowledged holding things back from their spouses and also that open communication had become more difficult.

Therefore, the role of communication, whilst it is recognised to be important, requires further investigation for couples facing dementia with regards to how different stages are reached and maintained, and how communication styles may be influenced by prior relationship communication, coping styles and progression of the disease among other factors.

3.3.2.4 Relationship-focused coping

Although practical and emotion-focused coping strategies remain the two primary methods of coping reported in the literature, DeLongis and O'Brien (1990) introduced a further set of strategies for coping that focus on regulating and maintaining social relationships, called Relationship-focused coping. This includes strategies such as negotiating with loved ones, compromising with loved ones, being empathic (DeLongis and O'Brien 1990, Kramer 1993), reprioritisation (Wright 1993), revaluation of self and relationships, focusing on manageable challenges, downplaying the constraints of the illness, maintaining a sense of control, focusing on the present (Lyons et al 1995),

active engagement, overprotection and protective buffering (de Ridder, Schreurs and Kukjer 2005).

Research into relationships also shows that some seemingly maladaptive strategies may actually be conducive to coping within couples. For example, seeing the person with dementia as 'not the person I married', may be a coping strategy that allows carers to preserve good memories (Lewis 1998, Baikie 2002). Conversely though, Langner (1995) warned that personal growth may be more likely in carers who had accepted the loss of who their spouse used to be. Therefore, these studies have conflicting findings and furthermore do not consider the impact of this strategy on the person with dementia. Future research should attempt to investigate the impact of coping strategies on both partners within a couple.

The importance of emotional support has also been identified in the literature (Arksey, Hepworth and Qureshi 2000). However, while Sormanti and Kayser (2000) agreed that the presence of emotional support fostered growth in spousal relationships in which the wife had cancer, they found that emotional support was least readily offered by husbands compared to other types of support such as practical support. Unfortunately, the authors did not appear to have asked the husbands whether they considered themselves to be providing adequate emotional support, so it is unclear whether they were not or whether this reflects differing needs between husbands and wives. Nonetheless, the provision of emotional support in relationships should receive further attention, particularly for couples facing dementia.

Perry (2002) has attempted to do this with regards to wives whose husbands had dementia. She found that the spousal relationship is well placed to allow adjustment to dementia whilst maintaining the identity of the person with dementia where possible. She found that wives achieved this through using their prior knowledge of their husbands to initially recognise that things had changed. Furthermore, they continued to use their knowledge of their husbands to begin to take over from them where necessary and as a result, created new identities for themselves and their husbands. This enabled them

to develop strategies for coping day to day, such as manipulating the environment and ensuring that they knew where their husband was. Running throughout the interviews in this study was the sense that wives often continued to see themselves as a couple and recognise the aspects of their husbands that were representative of their old selves. This was also reported by Hellstrom et al (2005) who found that carers focused on the remaining skills of their loved one.

More recently, research has been published that proposes that healthcare professionals could work with the strengths of couples and families facing dementia, in interventions designed to facilitate coping (Yarry, Judge and Orsulic-Jearas 2010). The authors used a strengths-based inventory to identify strengths already existing within the relationship, and then used those strengths to develop new skills. Within the examples given in the paper, Yarry et al illustrated how this intervention helped dyads to maintain independence and engagement, and manage caregiver stress. Therefore, Yarry et al's study is an example of how research that embraces individuality in dementia, is of great benefit to further understanding of the experiences of people with dementia and their families, and how researchers can use this knowledge to develop efficacious interventions.

3.4 Conclusion

Research into dementia spans several areas and specialisms, but can be abridged by four core areas: cause, cure, care and prevention. These are the four areas defined by the Alzheimer's Society within their funding programme for research into dementia.

Historically, where researchers have attempted to improve understanding of the experience of dementia, there has been a lack of direct involvement of people with dementia, with much research using input from carers instead. Methodologically there have been two main factors which have deterred researchers from including people with dementia in this type of research. Firstly, obtaining informed consent from people with dementia is inherently

fraught with ethical dilemmas. This is because dementia causes cognitive deficits to memory and reasoning skills which can make it difficult for people with dementia to take in all the information about a study and then consider it for long enough to make an informed choice about whether they want to take part. However, researchers more recently have made attempts to overcome this, for example by taking informed consent at different stages throughout the research process to ensure the participant is still happy to take part. For a person with dementia who is too severely impaired to provide informed consent, often a family member makes an informed assent on their behalf.

Secondly, it can be difficult to include people with dementia when a study is collecting retrospective data. In these cases, if the research is concerned with facts, researchers may be concerned that the data they receive from people with dementia may not be wholly accurate. As a result, researchers usually rely on carers for retrospective information. Indeed, it is only relatively recently that researchers have been making an effort to overcome such obstacles. Although, as more work with people with dementia is completed and published, the importance of including this population in this area of research is gaining recognition.

For example, while Hubbard, Downs and Tester (2003) reported that people with moderate to severe dementia are rarely interviewed in research due to problems with speech, vocabulary, linguistic reasoning and discourse, this does not mean that people with moderate to severe dementia have nothing to offer researchers. Indeed, some researchers have confronted this dilemma directly by addressing the reliability of people with dementia's input into research. For example, Trigg, Jones and Skevington (2007) found that people with mild to moderate dementia were able to use a self-report tool (Bath Assessment of Subjective Quality of Life in Dementia BASQID) to provide reliable answers to questions about their quality of life.

Indeed, the last ten to fifteen years have seen people with dementia become more central to research which is about them: their experiences, feelings, perspectives and beliefs (Hellstrom et al 2005). In support, Downs (1997)

highlighted a move towards recognising the value of people with dementia's input into research, specifically with reference to their sense of self, their rights and their perspectives. She cited a move away from carer-dominated research and also a move away from seeing people with dementia as 'sufferers' or 'victims' towards one that acknowledges them as active care recipients who can contribute to research. Furthermore, Epp (2003) reported on a shift to 'person-centred care' in dementia research which aims to focus on the whole person and their remaining abilities as well as that person within the wider contexts of family, marriage, culture, ethnicity and gender. Moreover, Hellstrom, Nolan, Nordenfelt and Lundt (2007) reported that research has shown that people with dementia may themselves find benefit from taking part in research in ways such as feeling valued, validated and capable.

This involvement of people with dementia should be reflected in all types of research and policy making. Indeed, the involvement of people with dementia and their carers on the committee which developed the UK National Dementia Strategy is encouraging. The following quote shows that both quantitative and qualitative research is needed in order to gain the most out of the research process with regards to dementia. Perry (p.308, 2002) points out that '...quantitative studies enriched the understanding of caregiving; however they did not yield a rich view of the experience of caregiving or the process of becoming a caregiver.' Therefore, in order to achieve a rich view of the experiences of people with dementia and their loved ones, it is important to conduct qualitative research.

Research into the impact of dementia on couples is also limited due to the historical reluctance to include people with dementia directly in research. Furthermore, research generally focuses on people with dementia and their spouses as living parallel lives rather than focusing on them as a couple. Therefore, knowledge about the needs of couples facing dementia is limited because 'Few studies attempt to combine the perspectives of the people with dementia and their partners' (Davies and Gregory 2007 p.484). Sheard (2004) noted a lack of work towards exploring what 'being together with dementia' actually means. He emphasised the importance of remembering that people

exist in relation to other people and not to exclude them from research, a view supported by Hellstrom et al 2005, Quinn et al (2008) and Quinn et al (2009) among others.

In a recent systematic review of studies into how the quality of the relationship between people with dementia and their carers influences their experiences and well-being Quinn et al (2009) concluded that relationship quality can play an important role in coping with dementia for carers, although the role for people with dementia is less clearly defined, mainly because research has yet to ask them directly. Indeed, Braun et al (2009) indicated that “relatively little is known about how caregiver and care receiver variables interact” (p.426) and suggest that “studies actually referring to both partners are indeed the only possibility to get insight into caregiving dyads” (p.428). The couple relationship is also unique in that it affords the appreciation of the ‘before’ and ‘after’ narrative which comes from intimate knowledge and understanding of their partner (Galvin et al 2005). Thus, it is important that future research attempts to access this relationship if researchers and clinicians are to further their understanding of the experience of dementia for couples.

This is reiterated by DeLongis and Holtzman (2005) who reported “Without an examination of how stress is coped with within the context of these close relationships, we are unlikely to ever fully understand why and how some people thrive in the face of stress while others flail.” (p.3). Similarly, Braun et al (2009) suggested that “getting a better knowledge of the dementia caregiving dyad should be of great relevance for future research” (p.434).

This chapter presented models that describe and explain the process of adjustment for couples, and four key areas of research pertinent to couples coping with dementia were identified and new avenues for research illustrated.

3.5 Aims

Coping with dementia can be a difficult process at times, and that whilst the challenges faced by people with dementia and their spouses can be different,

the relationship between them seems to be a valuable asset in a couples' coping arsenal. However, research into the spousal relationship in dementia is currently in its infancy, with recent systematic reviews calling for increased knowledge of the caregiving dyad in dementia, with equal credence afforded to both people with dementia and their carers. Therefore, this thesis aims to explore how people with mild dementia and their spouses experience and cope with dementia. Therefore, this thesis aims to address two questions:

1. How do couples (in which one partner has mild dementia) experience the impact of dementia on their lives and relationship?
2. What coping strategies are employed by couples (in which one partner has mild dementia)?

- **Chapter 3** introduced the reader to coping with dementia, with regards to people with dementia, carers and the couple relationship.
- Definitions of coping were provided, both generically and with regards to chronic illness. Coping is influenced by the nature of the stressful event, the social context in which it occurred and personalities of those involved.
- Two main types of coping strategy are problem-focused and emotion-focused. Both play a role in successful adaptation to chronic illness. The understanding of the efficacy of coping strategies, particularly for couples, deserves more attention.
- Models which detail the process of adjustment for people with dementia and carers commonly share one feature that is that they seek to reach a balance. Otherwise termed 'acceptance', 'normalisation', 'maximising' or 'working through it'.
- A few attempts have been made to produce models of adjustment for couples facing dementia, although some of this research was conducted with carers only, which although provides carer insight into couples in dementia, is lacking a dyadic component which would take both partners' experiences into account.
- Key features of coping within couples were identified from the literature. Firstly, literature currently supports the view that awareness about the diagnosis of dementia and its implications for couples is important.
- Secondly, research predicts that the balance of mutuality is often affected by dementia. The ability for couples to work together was found to be important in the maintenance of mutuality.
- Thirdly, communication within couples was found to be important, with communication styles predicted to change along with the process of adjustment.
- Lastly, in addition to problem- and emotion-focused coping, relationship-focused coping which focuses on maintaining the couple relationship, through emotional support and compromise is associated with positive outcomes for couples.
- The need to focus on both members of a couple is paramount for future research in order to improve understanding about how couple dynamics influence the experience of dementia for both partners.
- This thesis aims to explore how people with mild dementia and their spouses experience and cope with dementia through two research questions:
- 1. How do couples (in which one partner has mild dementia) experience the impact of dementia on their lives and relationship?
- 2. What coping strategies are employed by couples (in which one partner has mild dementia)?

Chapter 4

Methodology

The purpose of this thesis is to explore how couples (people with mild dementia and their spouses) describe their experience of dementia and how they try to cope with it. In order to achieve a richer understanding of the experience of dementia for couples, both partners were included equally in this research.

4.1 Research questions

1. How do couples (in which one partner has mild dementia) describe the impact of dementia on their lives and relationship?
2. What coping strategies are employed by couples (in which one partner has mild dementia)?

4.2 Theoretical perspective

The theoretical perspective of this thesis is embedded in the data analysis technique that was used. Interpretative Phenomenological Analysis (IPA: Smith, Jarman and Osborn 1999) is particularly suitable for this study since it aims “to explore in detail the participants’ view of the topic under investigation” (Turner, Barlow and Ilbery 2002, p289) and “may help to illuminate the subjective perceptual processes involved when an individual tries to make sense of his or her health condition” (Smith et al 1999, p219). This study takes a phenomenological approach because it recognises that “what respondents say does have some significance and ‘reality’ for them...that it is part of their ongoing self-story and represents a manifestation of their psychological world, and it is this psychological reality that one is interested in” (Smith 1995, p.10). Therefore, providing a data collection method which allowed and encouraged participants to tell their story, and a data analysis method which upheld the importance of their narratives, was an integral aspect of this study.

This approach has successfully been used in dementia research (Clare 2002, Quinn et al 2008) and in research into the impact of other chronic illnesses on couples specifically. For example, Mann and Dieppe (2006) analysed data from 12 couples in which one partner had rheumatoid arthritis, Mahrer-Imhof, Hoffmann and Froelicher (2007) conducted IPA on interview data from 24 couples in which one had cardiac disease, and most recently Rodham, Rance and Blake (2010) analysed data from 4 couples where one partner had Fibromyalgia.

Smith et al (1999) proposed the 'ideographic case-study approach' to IPA which is appropriate for "the exploration and development of shared themes" (Fade, 2004 p.648) in a small number of participants. This was the approach used in this study because although n=24, the analysis focused on a maximum of twelve cases at a time i.e. 12 people with dementia, then 12 carers, then 12 couples.

The ways in which this study adhered to these principles on a practical level will be described in more detail throughout this chapter.

4.3 Definition of terms

The two key terms that will be defined here are 'coping' and 'carer'. This will enable these terms to be put in context for this thesis and thus allow the reader to make sense of these concepts appropriately.

This thesis takes the view that *coping* is defined as a behavioural or cognitive response to stress, in that individuals either try to change the situation or their emotional response to the situation, as is generally accepted in the literature presented in Chapter 3 (Folkman et al 1986, Matson 1994, Patterson and Garwick 1994, DeLongis and Holtzman 2005). At the outset, the researcher attempted to keep an open mind about what might constitute a 'coping strategy' so as not to miss something important that may not have fit into this general definition of coping. In order to achieve this, the identification of coping strategies within this study was done by focusing closely on the narratives of

the participants because this thesis seeks to understand their perspectives or 'truth'. . Participants were encouraged in the course of the interview to demonstrate their interpretation of the term coping. Thus, attempts were made to understand how participants represented coping as they illustrated their story

'Coping strategies' were defined as any attempt described by the person with dementia/carer to help them cope with challenges imposed by dementia. For example, this included direct action to change the situation as well as altering their perceptions of their situation (Folkman et al 1986, Keady and Nolan 1995 and DeLongis and Holtzman 2005).

This thesis has used the term 'carer' to refer to the spouse of the person with dementia. Previous research illustrates the use of several different labels with which to define this group of people: 'carer' (Galvin et al 2005, Searson et al 2008), 'family carer' (Hutchings et al 2010, Clarke et al 2010), 'spouse carer' (O'Shaughnessy et al 2010), 'spouse caregiver' (Narayan et al 2001, O'Donnell 2000, Ott et al 2007, Yarry et al 2010), 'family caregiver' (Berg-Weger et al 2001, Smith 2009), 'spouse' (Hellstrom et al 2005, 2007, Marwit 2005), and 'caregiver' (Clark and Bond 2000, Gates 2010).

This thesis takes the view that the *carer* is the spouse of the person with dementia. This was primarily done to remain in-keeping with the definition that the participants were used to. Each carer in this study had been introduced to this term through their involvement with the Memory Clinic, whereby the term 'carer' is widely used to refer to the family member/s and/or friends who support the person with dementia. The Memory Clinic accepts that it can be confusing or felt not to be relevant to carers of Memory Clinic service users because it can conjure up thoughts of formal caring roles such as those involved in helping with personal care. Furthermore, because carers are primarily spouses or other close family members, they often do not consider their caring role to be anything beyond what they would naturally do anyway, and cite their motivation as being one of 'love and concern' (Smith 2009 p.70). For others, however, the transition from relative to carer can be a

difficult process, both emotionally and practically. This was more reason for using a fairly generic definition of 'carer' in this thesis, which focused only on the fact of their role as a loved one supporting their husband or wife as opposed to inferring what specific roles the carer may hold.

Therefore, it is important for practitioners to explain what the term 'carer' means in this setting, and this is routinely done during Memory Clinic appointments. The importance of the 'carer' in the setting is also explained in terms of a triangle of care which involves the person with dementia, their carer and the Memory Clinic. This was discussed with carers in this study and they were told that they would be referred to as 'carers' but that this did not suggest that they necessarily performed any sort of formal caring role for their husband or wife. As the carers in this study were all aware of this term and were used to being referred to in that way, this did not pose any difficulties.

4.4 Recruitment

Purposive sampling was employed in order to intentionally select participants that would provide a rich diversity of experience. Silverman (2001) points out that while this "allows us to choose a case because it illustrates some feature or process in which we're interested", it also "demands that we think critically about the parameters of the population we are interested in and choose our sample carefully on this basis" (Silverman 2001, pp. 250). This type of sampling is used for studying cases in depth (Patton, 1999), and is therefore appropriate for this study since it aims to address the impact of dementia in an exploratory fashion. This strategy allowed the researcher to gain a mixture of different types of dementia, different ages and gender. Whilst this may compromise the ability for this research to be generalised, generalisation is not a key component of qualitative work. Therefore, it was felt that a diverse group of couples would help inform this research and potentially unearth differences in the ways that couples experience and cope with dementia, which would improve understanding overall.

4.4.1 Inclusion criteria

- One member of the couple had a diagnosis of mild dementia as defined by ICD-10 (International Classification of Diseases) criteria and / or DSM IV (Diagnostic and Statistical Manual) criteria.
- The 'mild' aspect of dementia was indicated by a score of a 21-30 inclusive on the Mini Mental State Examination (Folstein et al 1975) memory assessment, in accordance with NICE guidelines (National Institute for Clinical Excellence, 2006).
- The person with dementia and their spouse were both willing to take part in the study.
- Both members of the couple recognised that they/their spouse had memory problems. This was determined by the researcher during their routine memory clinic appointments, part of which involved discussing how they were coping with issues associated with their memory problems.
- The person with dementia could contribute to conversation by articulating ideas and feelings.
- They were a couple as opposed to platonic friends or other family members. Therefore, it was not essential that they were married.
- They lived together at home or in sheltered accommodation.

Suitable participants were identified from the Memory Clinic at Victoria Hospital, Swindon. During their visit to the clinic, the researcher was able to determine whether they would be suitable for an interview-based study by establishing whether the patient suffered from any speech problems and whether they recognised that they had memory difficulties. People with speech problems were excluded because this may have proved an impediment to this study which relied on tape-recorded interviews. This also applied to their spouse who was also interviewed as part of their routine appointment at the clinic.

The researcher would not approach a couple to be involved in the study if either spouse found that talking about it was not at all helpful or they were not

ready to accept the diagnosis. It was felt that although denial is an example of a coping strategy which may be useful to study, that it may not be in the person's best interest to be encouraged to talk about something that they had not yet come to terms with. Although it is fundamental to this study that we understand how people cope in different ways, it is also imperative that further knowledge is not gained at the expense of participants' well-being.

Following observation during their appointment at the Memory Clinic, participants who met the inclusion criteria were approached either in person or by telephone and asked if they would like to receive more information about the study. If they agreed, they were sent an Information Sheet (see Appendix Three) and were given at least one week to read it before the researcher contacted them again. She then telephoned them to answer any questions they had and asked if they were interested in taking part. If they wanted to take part, the researcher arranged to meet with each couple either at their home or at the Memory Clinic, according to their preference.

In the last decade, qualitative research in dementia has increased as the reliability and validity of people with dementia's subjective accounts has become readily accepted by researchers. In a series of studies where qualitative interview data was obtained for people with dementia or carers, sample sizes were as follows: Sabat and Harre (1992) 2 people with Alzheimer's disease, Gates (2000) 9 carers, O'Donnell (2000) 12 carers, Proctor (2001) 4 people with dementia, Clare (2002) 12 people with dementia, Perry (2002) 20 wife carers, Beard (2004) 3 people with Alzheimer's disease, Kirsi et al (2004) 13 husband carers, Ohman and Soderberg (2004) 14 carers, Harman and Clare (2006) 9 people with dementia, Sandberg and Eriksson (2007) 3 carers, Keady et al (2007) 1 person with dementia, Furlong and Wuest (2008) 9 carers, Quinn et al (2008) 34 carers, Westius et al (2009) 21 people with dementia, Hayes et al (2010) 13 caregiver husbands and 15 caregivers wives, Hutchings et al (2010) 12 people with dementia or memory problems and 11 carers, O'Shaughnessy et al (2010) 7 carers.

Where both members of a couple were included directly in research, sample sizes were: Pearce, Clare and Pistrang (2002) 20 men with dementia and their wives, Keady and Nolan (2003) 11 PWD and their family carers, Hellstrom et al (2005) 1 couple, Robinson, Clare and Evans (2005) 9 couples, Phinney (2006) 8 participant families, Vernooij-Dassen et al (2006) 18 couples, Hellstrom et al (2007) 20 couples, Daniels et al (2007) 1 couple, Clarke et al (2010) 4 people with dementia and their family carers.

Twelve couples (n=24) agreed to take part in this study. This is an appropriate number for qualitative work and fits into the range of sample sizes outlined above. This number is also suitable for the chosen qualitative method of analysis which will be discussed later in the chapter.

4.4.2 Description of recruited sample

Of the sixteen couples approached, twelve agreed to take part. Of the four couples who did not agree to take part, either one of both members of the couple did not wish to discuss their experiences of dementia. Therefore, because one of the inclusion criteria was that both members of a couple had to agree to take part, these couples did not enter the study.

The sample comprised eight males and four females with dementia, and their spouses. All couples were heterosexual. Age for the people with dementia ranged from 54 to 84. Nine of those people were diagnosed with Alzheimer's disease, one with vascular dementia, one with mixed dementia and one with multi-infarct dementia. At the first interview, time since diagnosis ranged from nine months to sixty-seven months and Mini Mental State Examination (MMSE) scores ranged from 21 to 27 out of 30, which is indicative of 'mild' dementia according to the NICE guidelines. Nine of the couples lived in their own homes and the remaining three lived in sheltered accommodation. All couples were married and had been so for 6 to 54 years. Eight of these marriages were first marriages and the remaining four were second marriages. Spouses of the people with dementia were not patients of the Memory Clinic, and therefore it was assumed that they did not have dementia. See Appendix

One for a table of sample demographics and background information for each couple.

4.5 Development of materials

This study was essentially an exploratory foray into the lived experience of couples facing mild dementia. Therefore, in order to respect the exploratory nature of this study as well as the theoretical perspectives behind it, a qualitative approach, in which participants were encouraged to discuss any issues they thought were relevant, was fundamental. This exploratory aspect of the study was particularly important in light of the limited research into how dementia affects spousal relationships from *both* parties' points of view (Robinson et al 2005, Quinn et al 2008, Braun et al 2009).

As reported in Chapter 2, recent research by Keady et al (2007) saw the development of a qualitative research method called co-constructed inquiry in which a healthcare professional works with the person with dementia to develop their life story script through which the interpretations made by the person with dementia can be identified. Keady et al (2007) argued that this allows people with dementia to understand the impact of dementia in context of the way in which they have dealt with issues across their lives. For the purposes of this thesis, the focus was not on building a script with people with dementia, but more on the understanding their lived experience of dementia. As a consequence, semi-structured interviews were more appropriate.

Therefore, it was appropriate for this study to conduct interviews with a number of couples to gain an insight into the lived experience across different couples facing mild dementia. Individual interviews were chosen over joint interviews or focus groups because the nature of the topic under discussion could potentially be difficult for some people to discuss in front of their spouse, or indeed other people generally. Therefore, it was decided that each member of the couples should be interviewed separately to ensure that they were able to say whatever they wanted to without fear of upsetting their spouse (Albitt, Jones and Muers 2009). Furthermore, Thomson and Williams (1982) point out

that researchers should not assume that husbands and wives agree, even on 'couple' characteristics that are those thought to be represented by one single value for the couple.

The researcher was fortunate to have input from a User/Carer Research Group which was run by the researcher and two colleagues at the Memory Clinic throughout this study's design, data collection and data analysis. This group was conducted on a monthly basis and the methodology for this study was developed in collaboration with this group. (See page 101 for more information)

This thesis adopted semi-structured interviews which ensured that certain topics were covered and also afforded the researcher and participant flexibility with regards to the order in which issues were discussed. This is congruent with the emotionalist perspective which "assumes that no fixed sequence of questions is suitable to all respondents" (Silverman 2001: p92) which is why the researcher made it clear to participants in the study that she had some questions to ask but essentially they should feel that they could lead the discussions as they wished.

Within the health care professional and patient relationship there is potentially a power imbalance between the health care professional and their patient. Within a research setting this may need to be addressed in order to ensure that there is space in interviews for issues to be brought up which were not contained within the interview schedule (Reed and Procter 1995, Silverman, 2001, Clarke et al 2010). The researcher attempted to do this as much as possible by conducting the interviews in a friendly and conversational way, and by asking participants questions about their lives which illustrated that as the interview was about their experiences, that they were the experts. This is also advocated by Smith (1995) in his outline of the interpretative phenomenological approach to qualitative interviewing (which was adopted in this thesis) in which he suggests that "the respondent can be perceived as the expert on the subject and should therefore be allowed maximum opportunity to tell his or her own story" (p.12).

Therefore, whilst semi-structured interviews meant that the researcher could incorporate issues identified as important in previous research conducted on the experience of people suffering with chronic illnesses and more specifically with dementia and their carers, the semi-structured nature also gave participants the opportunity to tell their unique story and raise issues which perhaps had not been previously identified.

The interview schedule was developed to provide as much opportunity as possible for participants to talk about their experiences without hindrance. It was important that participants felt comfortable talking to the researcher and safe in the knowledge that the interviews were confidential. It was felt that this was best achieved by providing a semi-structured format which was flexible and informal. With regards to the interviews themselves, couples were given the choice as to which member of the couple wished to be interviewed first, and in all cases, the person with dementia did so. There was no time limit imposed on the interviews in order to allow participants to discuss all that they wanted to without time restrictions. Interviews typically lasted around an hour, but ranged from twenty minutes to eighty minutes.

A tape recorder was used to record each interview. This ensured that the researcher did not miss potentially important pauses or overlaps. It also meant that the original data could be retrieved during the analysis phase in order to clarify the meaning of a sentence by determining intonation, for example. It is best used in conjunction with the researcher's field notes about body language and initial feelings about the interview (Silverman, 2001). Reviewing the tapes, one might find that their initial impression about an interview or part of an interview was mistaken. It is important to establish the participant's real meaning of an utterance or conversation in order for themes to be developed correctly. This is where being able to return to the taped interview is greatly beneficial for researchers.

Each participant took part in two interviews in order that the researcher was able to go back to issues brought up in the first interviews, and also address

further issues brought up by other participants. These issues were used to create the interview schedule for the second interviews, which was an on-going document during the data collection period. To see the full schedules for both first and second interviews, see Appendix Two.

It was important to conduct two interviews because it allowed further discussion on topics, which improved the researcher's understanding of the participants' experiences. This of course was essential in order to uphold the theoretical perspectives which both promote the understanding of lived experiences. The use of two interviews was also allowed the researcher to minimise the potential impact of tiredness on behalf of the participant, since it was not essential that all issues were covered at one meeting (Clarke et al 2010). Therefore, although participants took part in two interviews, their data was not treated as longitudinal data because the primary motivation behind doing a second interview (typically conducted within three months of the original interview) was to offer a further opportunity to improve understanding rather than review the differences between the two time points.

4.5.1 Development and piloting of interview schedules

An interview schedule was developed for the first interview using previous research as a guide to ensure that topics addressed by research into the experience of dementia were covered here. Smith and Osborn (2003) support the production of interview schedules in advance because this process not only encourages the researcher to think about what they hope to cover, but also allows them to identify any potential problems with regards to how topics might be introduced or phrased and how to manage problems should they arise. Questions included in the interview schedule were developed in line with guidance from Smith (1995) who developed the Interpretative Phenomenological qualitative approach that was adopted in this thesis. He suggested that interview questions should be neutral and not leading, that they should avoid jargon and that where possible they should be open as opposed to closed.

The interview schedule for the first interviews followed three main areas of discussion which covered their relationship with their spouse, their experience of dementia, and ways in which they attempted to cope with dementia. Each area had a number of sub-questions which were used when prompts were required. In order to further test the schedule in this study, it was piloted with two couples after which it remained static throughout the data collection period. The second interview schedule, on the other hand, evolved as the study went on. This meant that issues brought up by participants could be discussed with other participants in order to improve understanding of the lived experiences of couples facing mild dementia. The second interview therefore allowed concepts and ideas that were identified in prior interviews to be addressed in subsequent interviews.

Piloting interview schedules improves reliability ratings, Silverman (2001). By piloting the interview schedule with two couples over the course of two interviews each, this enabled the researcher to ensure that participants understood the questions and were able to articulate an answer. It also allowed the researcher to develop a manner of interview technique that, although being conversational, remained professional and confirmed to participants that their thoughts, feelings and opinions were of the utmost importance.

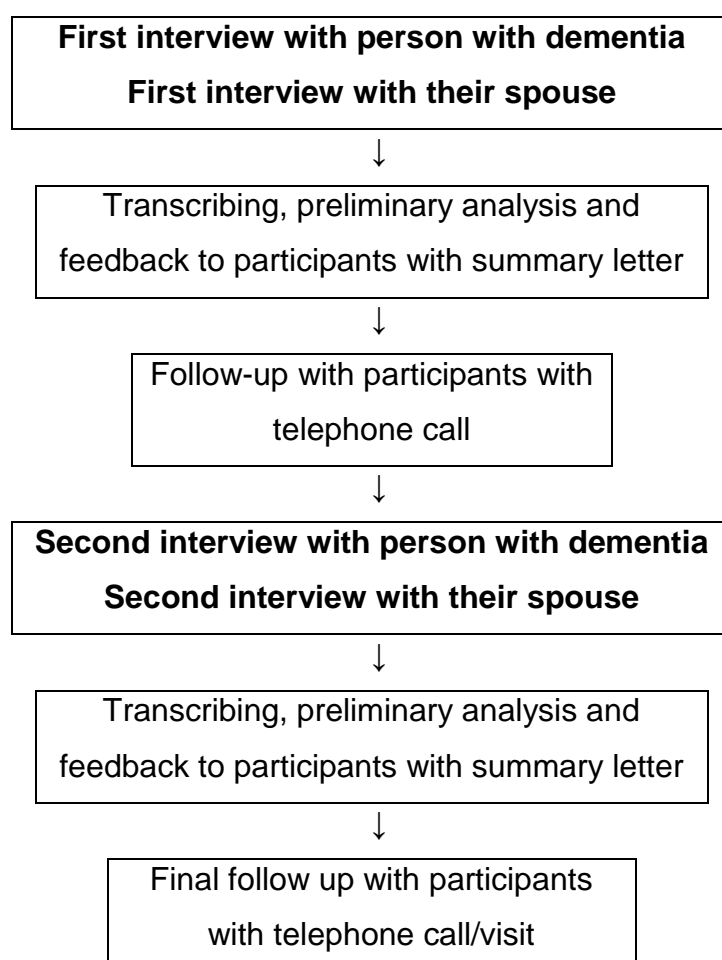
A conversational and informal approach was taken towards the interviews, and thus, the researcher did not necessarily ask the interview questions in the same way or in the same order for different participants. This was done in order to make participants feel relaxed, and to maintain an air of informality. This is advocated by the data analysis technique and theoretical perspective used in this study (Interpretative Phenomenological Analysis, Smith 1995) which denotes “the interview does not have to follow the sequence on the schedule, nor does every question have to be asked, or asked in exactly the same way of each respondent” (p.17). Indeed, participants involved in the pilot interviews found they enjoyed the experience, perhaps due in part to the fact that it was not presented to them as a test where they must answer specific

questions, but rather more as a chat so the researcher can try to understand their experiences a little better.

Essentially, the pilot interviews confirmed that couples felt the interview schedule questions to be relevant and important, so no changes were made to the first interview schedule. Piloting the interviews also confirmed that a conversational approach was well suited to this study in order to enable individuals to feel comfortable describing what were often difficult experiences.

4.6 Data collection

The following section will describe the procedure for data collection for this study, and where appropriate will explain the rationale for the chosen course of action. An overview of the procedure is given in Figure 1 below, following which it will be described in detail.



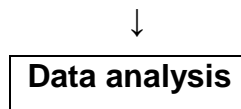


Figure 1: Procedure for data collection and analysis

4.6.1 Setting

The interviews took place at the couples' homes or at the Memory Clinic. Eight couples were interviewed at home and four at the clinic. In both instances, participants were interviewed separately in a room alone with the researcher. At homes, this room was the lounge or dining room, and in the hospital settings, clinical consultation rooms were used.

4.6.2 Prior to interview

Prior to each set of interviews, the researcher met with each couple and introduced herself by saying she was an Assistant Psychologist at the Memory Clinic and she was doing a PhD exploring the experiences of couples facing dementia. She outlined that the study would investigate how people with mild dementia and their spouses experience and cope with dementia, and that hopefully this information might aid the development of appropriate interventions for couples facing dementia. She also went through the ethics information sheet that they had been sent following verbal agreement to take part. The researcher reiterated that they could decide to withdraw from the study at any time without giving a reason.

Directly before each interview, the researcher went through the consent form (see Appendix Three) with each participant and answered any further questions that they had. Each participant was required to sign this form before the interview commenced. This was repeated before the second interview in order to ensure that each participant still consented to be involved. This adheres to one of the benchmarks for good practice when interviewing people with dementia whereby consent is taken throughout the research procedure (Hellstrom et al 2007). The researcher then asked them which member of the

couple would like to be interviewed first, and in all cases, the person with dementia went first.

She outlined the procedure for the interviews including the use of an audio tape recorder. Participants were told that the researcher had some questions to guide the discussion if needed. However, they were also told that they should feel that they could talk freely about the topic if they were happy to do so, because they were the experts after all. This introduction adhered to another of the benchmarks for good practice when interviewing people with dementia whereby researchers should endeavour to reduce the power inequalities between researcher and participant (Hellstrom et al 2007). This was also in-keeping with the theoretical perspectives of the study.

Almost all participants wanted the researcher to ask questions, at least to begin with. In these cases, the order of the interview schedule was adhered to and participants were given time to answer the questions and also the opportunity to take the discussion in other directions. In all interviews, all of the scheduled questions were covered.

4.6.3 During the interview

In order to uphold the theoretical principles of this thesis, the questions in the interview schedules were used as a guide and therefore while all the topics were covered during each interview, the manner in which the researcher asked the questions and the order in which the questions were presented, differed in response to each individual's communication style.

Indeed, establishing rapport and trust in an interview is paramount to achieving understanding which can lead to more informed research (Fontana and Frey 2000). The researcher achieved this by providing an informal interview style and emphasising that the participants were the experts. Prompts were used primarily as an aid to conversation. Interviews were conducted in a friendly, conversational way in order to encourage participants to talk about their experiences with minimal intervention from the researcher. Of course, this was

easier with some participants than others. The confidence of the researcher also developed with experience and she felt that this helped to instil confidence in the participants. From time to time gentle prompts were needed in order to encourage participants to expand or clarify what they were saying.

At the beginning of the second interviews, each participant was asked if they wanted to discuss any issues from the first interview or resulting summary letters.

At the end of each interview, the researcher asked if any issues had been raised during the conversation that they felt they needed further help with. Once one partner had been interviewed, the process was repeated for their partner.

At the end of each interview, couples were reminded what would happen next: the interviews would be transcribed word for word from the tape and then the researcher would write a summary letter which would be sent to them individually. Justification for using summary letters in place of the raw transcripts is provided in the 'quality of the research methodology' section of this chapter (p.97-104). Participants were asked to read their summary letter and make a note of any discrepancies, questions, mistakes and general thoughts. The researcher said she would be in contact when the interviews had been transcribed and the summary letters were ready. Couples were also given the researcher's contact details if they needed to contact her, and were reminded that they could withdraw from the study if they wished. Participants were again given the opportunity to ask questions.

4.6.4 After the interview

Shortly after interviewing each couple, immediate impressions were noted. Then each interview was transcribed word for word. This was done using a matrix to make finding and referencing quotes an easier process in the analysis stage. By restricting the transcript to the left half of the page, this

allowed room for thoughts and analysis to be easily incorporated onto the transcript itself.

If the researcher could not hear something that was said on the tape, a '?' was used. If several words were not understood '???' was used. A new line was started each time the researcher or participant spoke. If the researcher and participant spoke at the same time, this was noted in the right-hand section of the matrix.

Once the summary letters were ready the researcher contacted each couple and arranged to send them out. One week later the researcher contacted the couple and asked if there were any discrepancies with the summary of the interview and if it matched their perception of what had been discussed. If there were any discrepancies or issues, these were discussed and an agreement was reached with the participant. This contact was done primarily by telephone, although two couples responded to the offer of a face-to-face meeting. After discussing the summary letters from the first interviews, the researcher arranged a second meeting with them.

After discussing the summary letters following the second meeting, the researcher thanked them for their involvement in the study and ensured that they still had her contact details should they want to contact her. Participants were asked if they would like to receive a copy of the final report and their preferences were noted. They were also debriefed and given information about services that are available to them if they should need on-going support.

4.7 Data analysis

The analysis was conducted in three parts. The first part focused exclusively on the people with dementia, and the second part exclusively on carers. This provided an understanding of the similarities among people with dementia, and similarities between carers regarding their experiences of dementia (Maguire 1999). The final part of the analysis focused on couples which provided an understanding of this experience for couples as opposed to individuals. In

support, Maguire (1999, p214) states “To draw any conclusions about the relationship itself, the dyad must be used as the unit of analysis.”

Each set of transcripts was analysed consecutively in the order in which participants were seen (Fade 2004). For example, PWD 1’s interview 1 and interview 2 were analysed as one data set for the purposes of analysis. The way in which the analysis was conducted remained the same for each of these groups, and is outlined in detail below.

It should be noted that as the data collection period progressed, preliminary analyses were conducted on transcribed interviews in order to help inform the second interviews and ensure that important ideas were being discussed and not missed. Preliminary analyses consisted of insights and observations being noted in the right-hand margin of each transcript. Where interesting ideas emerged, they were added to the interview schedule for the second interviews (as described above).

Within the transcripts, and throughout the thesis, participants were referred to as PWD (Number) and Carer (Number), for example ‘PWD 1’.

4.7.1 Process of analysis

In line with Smith et al (1999) a five-step approach to the analysis of the interviews was taken. This process was first undertaken for people with dementia and carers separately in order to identify themes that were representative of the experiences of people with dementia, and the experiences of their carers. This process is outlined below.

1. Each transcript was read a number of times and any comments that were interesting or possibly significant were noted in the right hand margin.
2. Emerging themes or key words were noted in the left hand margin. This was done for both interviews for each participant. As further participants’ transcripts were analysed in this way, often the same themes were identified. However,

when new emerging themes were identified the researcher went back to previous participants' transcripts to check whether references to these newly identified themes had been missed.

3. For each participant, the emerging themes from the left hand margin were written into a list which was used to look for connections between these themes. The aim of this process was to define clusters of themes and if possible to identify a superordinate theme/s that tied a number of clusters together. At each stage of the analysis, the development of themes was checked with the transcripts to ensure that themes truly represented what the participants had said. Therefore, at the end of this process, each participant (and their set of two transcripts) had a list of emerging themes, with possible clusters and superordinate theme/s also identified.

During these initial steps of the analysis, the researcher received input from two other qualitative researchers who independently analysed one set of interview transcripts, in order to improve the trustworthiness of the data. Findings were discussed with the researcher, and it was reassuring that similar themes and ideas had been identified. These discussions also proved useful in encouraging reflection regarding preconceived ideas.

4. The next step was to develop a master list of themes that were ordered in a logical way which represented superordinate themes, clusters and themes. Again, this was done first for people with dementia, and then for carers. There were a number of steps to this process, which will be outlined below.

The possible clusters and superordinate themes identified in each participant's interviews were condensed into one list. Of course, some clusters and superordinate themes appeared on several of the participants' lists because they were well represented in the transcripts. Plastic wallets were then created for each cluster. All quotes that had been identified as representing a cluster were then printed and cut out individually. Each quote was identified by the participant's number and a number that signified whereabouts in the interviews the quote had been taken from. Each quote was put into the plastic wallet

relevant to the cluster which that quote represented. Where a quote did not fit any of the existing clusters, either a new cluster was identified or the quote was put to one side. All quotes that were put to one side were revisited at the end of this process.

During this process, the researcher was selective about the themes that were chosen to comprise the list of master themes. This was primarily determined by the prevalence of evidence in the data and therefore the ability of a theme to demonstrate shared experiences. However, the richness of data of individual quotes and whether themes were useful in exploring the overall premise of this thesis were also considered, as recommended by Smith et al (1999). Despite an element of selection, the emphasis at this point in the analysis was on over-inclusion to minimise the chances that something important may be overlooked. In order to improve the trustworthiness of this analysis, part of this process was done in conjunction with the first supervisor.

When all relevant quotes had been allocated to the relevant cluster, this information was then put into electronic format using the cut and paste function. This whole process provided the researcher with a rich understanding of what constituted each theme which encouraged further consideration as to how the clusters fit together. This facilitated the final step of identifying superordinate themes that represented a number of clusters. At this point the researcher had a master list of themes which were ordered in a logical way and represented the shared experiences of people with dementia and the shared experiences of their carers.

5. The final stage of the analysis took part during the writing up of results. Smith et al (1999) support the idea that analysis should continue into the writing up stage because continuing to view data with a questioning mind can make interpretations richer. At the outset it was necessary to consider how the themes that had been identified during Step 4 of the process could be woven into a logical narrative. This process encouraged improved understanding into the ways in which themes complemented each other, which added further clarity to the write-up. At this point, quotes were chosen to be included in the

finished article because they represented the “essence of recurrent themes or provided the most powerful expression of any given recurrent theme” (Dickson, Knussen and Flowers 2008, p.463).

The focus for the second part of the analytical process was on couples. This consisted of further analysis of the interview transcripts, and although essentially the same five step process was followed as for the individual analysis, the dyadic nature of the analysis meant that it was slightly different. The procedure for couple analysis is outlined below

1. Each couples' transcripts were read a number of times and any comments that were interesting or possibly significant were noted in the right hand margin.
2. Emerging themes or key words were noted in the left hand margin. This was done for both members of each couple. Where an issue had come up in one partner's transcripts, the other partner's transcripts were searched to see if there was any reference to this issue and where there was, each partner's perspective on the issue was compared. This allowed the researcher to address questions such as, whether partners agreed on the importance of the issue raised. This provided a rich understanding of the salient issues for each couple and how they were managed within the relationship.

As further couples' transcripts were analysed in this way, often the same themes and issues were identified. However, when new emerging themes were identified the researcher went back to previous couples' transcripts to check whether references to these newly identified themes had been missed.

3. For each couple, the emerging themes from the left hand margin were then written into a list which was used to look for connections between these themes. The aim of this process was to define clusters of themes and if possible to identify a superordinate theme/s that tied a number of clusters together. At each stage of the analysis, the development of themes was checked with the transcripts to ensure that themes truly represented what the

participants had said. Therefore, at the end of this process, each couple had a list of emerging themes, with possible clusters and superordinate theme/s also identified.

4. The next step was to develop a master list of themes that were ordered in a logical way which represented superordinate themes, clusters and themes. There were a number of steps to this process, which will be outlined below.

The possible clusters and superordinate themes identified for each couple were condensed into one list. Some clusters and superordinate themes appeared on several of the couples' lists because they were well represented in the transcripts. As with the individual analysis, quotes were chosen that represented shared experiences as well as richness of data. This information was then put into electronic format using the cut and paste function. This facilitated the final step of identifying superordinate themes that represented a number of clusters. At this point the researcher had a master list of themes which were ordered in a logical way and represented the shared experiences of couples in which one partner had mild dementia.

5. The final stage of the analysis took part during the writing up of results, and as with the individual analysis, it was first necessary to consider how the themes that had been identified during Step 4 of the process could be woven into a logical narrative. This process encouraged improved understanding into the ways in which themes complemented each other, which added further clarity to the write-up.

At the time of writing, this approach to analysis with regards to couples facing dementia was unique in that both individual and couple analysis was undertaken and an exploratory approach was used at the outset.

4.8 Quality of the research methodology

It is important for research to demonstrate its quality in order for its findings to be accepted with confidence. In quantitative research, the standards by which quality is measured are fairly standardised. However, this is not so clear cut with regards to qualitative research both because the use of qualitative methods is relatively more recent, and because qualitative research includes a vast diversity of methods. Thus, Yardley (2000) argued that it is necessary to “...consider how the value of a piece of qualitative research should be assessed” (p.215). In order to address this, Yardley developed a list of four key characteristics which she argued constitute good qualitative research. This section will be structured around these characteristics in order to illustrate how this piece of research constitutes ‘good’ quality qualitative research.

4.8.1 Sensitivity to context

This thesis illustrates its sensitivity to context in a number of ways that were defined by Yardley (2000) as measures of good qualitative research. First, this thesis is sensitive to the context of existing knowledge in the field. This is demonstrated throughout the first three chapters which together provide a review of the literature relevant to the experience of couples in dementia. These chapters outlined the current theoretical understanding of the impact of dementia on people with dementia and their spouses, as well as their attempts to cope with it. Yardley (2000) argues that this understanding is crucial if researchers are to improve theoretical knowledge of the topic at hand.

Yardley (2000) also argues that researchers should be sensitive to the socio-cultural setting of the research. In this case, participants had attended a Memory Clinic from which they were recruited to the study. Participants were interviewed by the researcher who was also a practitioner at the Memory Clinic. Thus, participants already knew the researcher in her role as an Assistant Psychologist, and she can therefore be thought of as an ‘insider practitioner researcher’ because the research was conducted within the setting in which she also worked as a health care professional (Reed and Procter

1995). This had implications for research design, data collection and data analysis which will be discussed throughout this section on quality.

In terms of sensitivity to context, the researcher was aware that a potential power imbalance present within the 'practitioner and patient' relationship could transcend into the 'researcher and participant' relationship. This is outlined by Skeil (1995) as an example of a negative insider bias. In order to overcome this as much as possible, the researcher emphasised the role of the participant as the 'expert' and encouraged them to tell their story. There was also an emphasis on being able to take their time which was different to clinic setting in which time constraints are present. The research was presented to participants as the researcher's chance to really understand the experience of dementia from the participants' point of view as opposed to the health care professional leading the consultation as was the case during clinic. It may also have helped that the researcher was not a doctor, but an 'Assistant Psychologist'. The 'assistant' part of the title suggests a more junior role, which may have made it easier for participants to take on the notion of being the expert. Participants were also told that taking part in the study would not affect their treatment in the clinic in any way.

Being an insider practitioner also has its positive biases as identified by Skeil (1995). In terms of sensitivity and context, the researcher had the benefit of knowing the participants prior to the research taking place, and as such was able to tailor her interview technique to each person to ensure maximum rapport. This knowledge of the participants also allowed the researcher to understand their comments in context of them as people, for example how they usually behave during interviews, the nature of their impairments and how they affect their daily life, their backgrounds and their characters. Furthermore, from the participants' view, Skeil (1995) argued that it is often easier to talk to someone they know rather than a stranger.

4.8.2 Commitment and rigour

Yardley (2000) defines 'commitment' as encompassing "prolonged engagement with the topic, the development of competency and skill in the methods used, and immersion in the relevant data" (p. 221).

Certainly, as a practitioner researcher it can be argued that the researcher had prolonged engagement with the topic. Indeed, Reed and Procter (1995) argued that "...practitioner researchers are part of the culture both before and afterwards." (p.5). Thus, the researcher had a clear understanding of dementia and a good appreciation of the many ways in which it can affect people from her experience as a clinician. Reed and Procter (1995) point out that it is impossible for the practitioner researcher to ignore this knowledge and experience, but that they should be aware of the ways in which it may influence the different stages of the research. Reed and Procter (1995) argued that there are two central themes which practitioner researchers must consider when devising and conducting research. The first is the relationship between the researcher and the research participants, and the second is the relationship between the researcher and the data.

As outlined above, the researcher made efforts in order to ensure that the relationship between the researcher and participant emphasised the role of the participant as the expert. In addition, and with regards to commitment and rigour, the researcher had considerable competency and skill in conducting semi-structured interviews and discussing sensitive issues with people with dementia and their families as a result of her time working in the Memory Clinic. Thus, it can be argued that this thesis fulfils the necessary competency and skill base in order to be thought of as an example of good qualitative research.

Yardley's (2000) final aspect of commitment and rigour is the immersion in relevant data. This encapsulates the second area of consideration for practitioner researchers which is the relationship between the researcher and the data. Skeil (1995) outlined that it is important for practitioner researchers to

ensure that only data collected during the research is used in the data analysis, and that for example, information gained during clinic is not. Care was therefore taken (in line with Smith and Osbornes's (1999) guidelines) to ensure that analysis was embedded in participants' transcripts and not in the researcher's insider knowledge.

In order to improve the trustworthiness of the study and ensure that the analysis was based upon the participants' opinions and experiences, summary letters were written for each member of the couples (see Appendix Four). The content of these letters were taken directly from the transcripts and included everything that was discussed in the interview. Participants' language was used where possible. A summary letter was sent to participants approximately one week before their second interview or one week before their final debrief telephone call or meeting.

The letter also explained that the summary letters were for each participant and if possible, participants should refrain from reading each others' letters, at least until the study was completed. It also stated that participants should not feel obliged to show their letter to their spouse. Lastly, it explained what would happen next.

There are several reasons why summary letters were used in place of providing participants with the transcripts, which are explained below:

1. The interviewees discussed a number of issues and experiences over the course of their two interviews and as a result, the transcripts from each interview average at about twenty pages long. Summary letters, on the other hand, average at about five pages, which makes the participant's job of reading them a little less arduous.
2. It was also felt that it was imperative to the trustworthiness of the process that the reviewing of the interview content should be done in a way that was accessible to participants. This was achieved by summarising each participant's interview in prose that closely matched the language they used. This was more user-friendly for people with

mild dementia than a lengthy transcript which may have been difficult to read and concentrate on sufficiently to note any discrepancies or thoughts

3. When writing the letters, care was taken to include everything that was discussed. At all times the researcher tried to do this in the participant's style, so that what was in the letter was as close to what that participant said as possible. However, the researcher is also aware that the process of writing a letter may lend itself to some degree of interpretation on her behalf since she was writing what she thought the participants meant, albeit while trying to keep close to their language. Indeed, the nature of the analysis is 'interpretative' and so the researcher interpreted the participant's interviews as a basis for the study. Therefore, the interpretative aspect of summary letters was in fact a benefit since it gave participants the chance to correct or clarify their meaning with the researcher.
4. It also gives participants the opportunity to disagree with the researcher. They might say 'I didn't say that' or 'I didn't mean that' because they don't have the transcript in front of them saying 'actually you *did* say that'. This gives people the opportunity to change their minds and think or argue that the researcher did not interpret it properly.

The trustworthiness of this thesis is also supported by its involvement in a User Carer Research Group which ran from the outset of this study up to the initial analysis stage of the process. This group was conducted on a monthly basis at the Memory Clinic and consisted of two members of staff and six to eight people with dementia and carers. At the meeting, different research projects were presented and discussed within the group. With regards to this thesis, the group had input to the study design, suggesting that interviews should be conducted individually in order to allow participants to speak freely. Group members also helped with funding applications, particularly where applications called for a 'lay summary'. The initial themes of the analysis were also discussed within the group

4.8.3 Transparency and coherence

Yardley (2000) argues that it is important for qualitative research to describe its coherence, which Yardley refers to as “the ‘fit’ between the research question and the philosophical perspective adopted, and the method of investigation and analysis undertaken.” (p.222). This has been achieved throughout this chapter, with a justification for the use of Interpretative Phenomenological Analysis (Smith, Jarman and Osborn 1999) in light of the research question at hand. In further support, Yardley (2000) proposed that “...if the aim of the research was to explore and give voice to the personal perspective of people suffering from a particular illness, a thorough phenomenological analysis of interviews with these sufferers could provide a consistent and complete description...”.

With regards to transparency, it is important for good qualitative research to offer a clear and detailed account of the research process, the decisions made and the reasons for these decisions (Yardley 2000). Such an account has been provided in this chapter, which details how the interview schedule was developed, the inclusion criteria, the practical process of the research, and how the data was analysed among other aspects of the research. Furthermore, in order to illustrate that the interpretations made through the use of Interpretative Phenomenological Analysis were justified from the data, verbatim examples of transcripts were presented in the results chapters of this thesis.

It is also important for qualitative researchers to illustrate some reflexivity with regards to their work, and in doing so acknowledge the impact it may have had (Yardley 2000). In this study, after each interview, the researcher made notes regarding reflections on her feelings towards the participants and how she considered the interview to have gone. This was especially important with participants with whom the researcher did not get on so well with, or whom she got on very well with. On these occasions, it was imperative that these feelings were defined and the researcher was aware of them so that the potential bias

during further communications with the participant or the analysis stage of the process, were limited.

Speaking more generally, there were two further areas which the researcher acknowledged had a major influence on this research. The first is the practitioner researcher element of this work whereby the researcher worked hard to overcome potential negative biases, as discussed above.

Secondly, the researcher had an experience with a piece of research prior to this study which highlighted how enthusiasm may blind the researcher from seeing things as they really are. During this previous piece of work, the researcher conducted a focus group on a topic, which at the time, she felt she had received positive feedback about. However, when she began to transcribe the audio tapes she realised that the focus group members had actually been less positive about the topic than she had perceived. Whilst at the time, this was seen as a disaster, it did help to ensure that the researcher was, from then on, most alert as to what her research participants were actually saying. This also led to the idea of using summary letters as a way of checking that the researcher kept as close as possible to the participants' opinions and thoughts, whilst accepting that an interpretative element of the analytical process was a key part of the analytical method chosen. Thus, the researcher acknowledged that there was an interpretative element to the data analysis but wanted to ensure that she approached the analytical process with the participants' voices imprinted firmly in her head.

4.8.4 Impact and importance

The final criterion that constitutes good qualitative research focuses on the importance of a piece of research in the wider context. This may refer to its contribution to knowledge, its practical benefit for the community which it addresses, or its socio-cultural impact with regards to attitudes and understanding (Yardley 2000).

This thesis made attempts to ensure its confirmability, for example, the use of summary letters to ensure that participants' views were well represented. Furthermore, the pilot interviews were interpreted by both the researcher and two external researchers at Oxford Brookes University, and the first supervisor at University of Bath. Similarities existed between all three interpretations and where differences occurred it was useful to discuss these opinions.

The ways in which this thesis adheres to this criterion with regard to its importance in the literature, and with regards to practice, will be presented in the final discussion chapter.

4.9 Ethics

This study was approved by Swindon Research Ethics Committee. See Appendix Three for information letters that were sent to potential participants and consent forms for people with dementia and carers. See Appendix Five for ethical approval letter. There are specific ethical concerns that have to be considered when doing research with people with dementia, which are outlined below.

There is some concern about the ability of people with dementia to make informed choices (Forbat and Henderson, 2003). For this study, the participants had a diagnosis of mild dementia, which meant that any memory or functional impairment was at a mild level. Therefore, participants were able to read and understand the information sheet enough to be able to explain to the researcher their comprehension of the study, what they would be required to do and whether they were happy to do this. A consent form was signed by all participants at each interview to give them the opportunity to ask any questions and demonstrate that the participant was still happy to take part.

In order to minimise the threat of spouses reading each others' letters, particularly between the first and second interviews, each participant was sent a summary letter that was addressed specifically to them. The letter also detailed that they need not show their letter to their spouse if they preferred not

to. In fact, in the summary letters of the first interview, the researcher asked participants not to read each other's letters so as to minimise any influence this might have on the second interviews. The researcher also talked to the participants about this at the interviews and outlined why it would be better for the research if they did not read each other's letters between the first and second interviews, at least. It was included in the letters to remind the participants and because it was felt that a written instruction may provide them with justification for keeping the details of their interview private, if they so wished.

Lest any of the participants became upset during the interviews, the researcher was able to access local support services, such as social services, or private enterprises such as Swindon Carers in order to ensure that participants received continued support if necessary. As an employee of the

Memory Clinic
Support Workers
groups if this
matter was
process of the
number of
for their access
the Memory

All participants
involvement
consent forms
be involved
During the interviews
and asked participants

The next three
will present
Chapter 8 will
in order to ensure

- **Chapter 4** introduced the reader to the theoretical perspective which underpins this thesis: Interpretative Phenomenological Analysis. Justification for this decision was presented.
- The terms 'coping', 'coping strategy' and 'carer' were all discussed and defined for the purposes of this thesis.
- Recruitment strategy, inclusion criteria and sample size were presented and justified.
- The recruited sample were then described.
- The development of materials was explained. This begun with justification for using semi-structured interviews followed by the development of the interview schedule.
- Piloting of the interview schedule was discussed.
- The data collection process was described, including the setting and what happened prior, during and after each interview.
- The method of data analysis (Interpretative Phenomenological Analysis) was justified and the process of analysis described in detail, both for individual and dyadic analysis.
- The quality of the methodology section presented the ways in which this study upheld components essential for good quality qualitative research – sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance.
- Ethical issues were described and solutions presented.

ect
all
ons
t at
y to
e.
was
d 6
way
tia

and carers as unique groups, before combining these experiences to determine how they contribute to the overall experience of dementia for couples.

- **Chapter 4** introduced the reader to the theoretical perspective which underpins this thesis: Interpretative Phenomenological Analysis. Justification for this decision was presented.
- The terms 'coping', 'coping strategy' and 'carer' were all discussed and defined for the purposes of this thesis.
- Recruitment strategy, inclusion criteria and sample size were presented and justified.
- The recruited sample were then described.
- The development of materials was explained. This begun with justification for using semi-structured interviews followed by the development of the interview schedule.
- Piloting of the interview schedule was discussed.
- The data collection process was described, including the setting and what happened prior, during and after each interview.
- The method of data analysis (Interpretative Phenomenological Analysis) was justified and the process of analysis described in detail, both for individual and dyadic analysis.
- The quality of the methodology section presented the ways in which this study upheld components essential for good quality qualitative research – sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance.
- Ethical issues were described and solutions presented.

Chapter 5

Results - People with mild dementia

This chapter presents the findings for the people with dementia (PWD) by looking at the common themes among their transcripts. The interviews were designed to explore the impact of dementia and how the individual attempted to cope with it. Therefore, this chapter is presented in two parts: the first addressing the impact of dementia, and the second addressing coping.

Within the focus of “impact”, PWD discussed the losses they had suffered, as well as changes to their relationship with their spouse and considering who they were. This led to the identification of three key themes: loss, relationship and identity. Within the focus of “coping”, PWD discussed emotional, practical and psychological ways of coping as well as aids they had employed to help them cope. From this, two key themes were identified as process of acceptance and aids to coping.

5.1 Impact

All of the PWD spoke about the negative impact of having ‘memory problems’ or ‘dementia’ or ‘Alzheimer’s disease’. However, the extent to which this had altered their lives depended on the nature of the impact, as well as the frequency and severity of the impact. Three themes relating to the impact of dementia will be described and illustrated using quotes from PWD’s transcripts. The first theme of ‘Loss’ highlights the personal losses that they endured as a result of their diagnoses. The second theme documents the way in which they felt that dementia had impacted on their ‘identity’. The third theme focuses on the impact of dementia on their ‘relationships’. Each theme is illustrated with a range of quotes from the people with dementia. Quotes were chosen that were representative of the theme being presented.

5.1.1 Loss

PWD mentioned two specific types of loss: memory-associated loss, and loss of ability in social situations.

5.1.1.1 Memory-associated loss

People with dementia often talked about practical difficulties they faced due to their memory loss. One example that repeatedly came up in interviews was being unable to remember names of people, places and objects.

PWD 3: I can watch telly and I thinks to myself, "I know that person", and yet for the love of me I can't think of his or her name. And then about half an hour afterwards I'll say "Ah! I know his name" see and that's how it gets me.

PWD 10: I can't remember things sometimes. I tried... I go to speak and I just can't get it out.

These quotes illustrate a sense of frustration among the people with dementia that was embedded in the feeling that they knew what they wanted to say but just couldn't find the right words or way to express it. PWD 10 remarked how he 'tried' to speak but couldn't. That he kept trying to speak despite being unsuccessful indicates that he struggled against his memory associated losses. Another PWD remarked on forgetting what he was doing.

PWD 9: The only thing is, you know, like previously I said I could go in the garden to get something, and when I get down there I can't think what the hell going down (laughs) what did I come down here for?... It's just a nightmare.

PWD seemed to make light of their experiences with regard to this type of forgetting by joking or laughing. However, despite this a shared sense of

frustration existed among these quotes and the people with dementia made it clear that memory associated loss is a major difficulty (“nightmare”) for them.

PWD tried to explain the mechanism behind their lapses in memory by talking about their mind going ‘blank’ or being ‘unable to focus’. This unpredictability made it hard for some of them to come to terms with.

PWD 3: I mean er, me mind loses concentration sometimes.

PWD 2: It'd suddenly go blank on a, know the person's face but you just forget the name, couldn't click it together.

PWD often talked about their memory as a separate entity from them, as shown by ‘me mind’ and ‘it’ in the quotes above. It was not them per se that was failing but rather a machine that was malfunctioning. This proved all the more frustrating when it happened in contexts with which they were very familiar.

PWD 6: I often get stopped by a person in a car saying “Could you tell me where such and such a street is?” I might be standing right on it and I wouldn't know it... I mean it's (pause) I been round here as a postman! (chuckles) I should know all the roads round here.

During the interviews, such distressing experiences were also commonly embedded in gentle humour which perhaps served to lighten the impact on the person with dementia as they told their story.

Whilst the people with dementia recognised their limitations, many also indicated a parallel sense of optimism about being able to regain skills that they recognised they were losing.

PWD 1: I've lost that, um, sort of thing that I treasure, possibly the most [to be able to write]... that's why I'll keep trying to get

better, to beat this thing, to be able to get my memory back, to be able to dream up things that I would write about, which I can't do at present.

This parallel process of realism (losing skills) and optimism (getting better) was not something that appeared to be a conscious process. However, one person with dementia described a moment of insight when he realised something was wrong. It was at this point that he became aware that he had been covering up his difficulties for some time, but almost automatically without really noticing.

*PWD 8: And I didn't realise I was covering it up myself. And it only came to me when, only recently, a year or so ago, that, when I sat in, in our house now and, in *** (village), and I didn't know where I was...and I just sat there, and sat there and sat there, and I couldn't remember the name of the place where I was. And I thought, well I started to cry, and *** (wife) said "What's wrong?" and I said, well I knew who she was and everything, I just didn't know where we were.*

Memory associated loss was certainly a big issue and something that the people with dementia felt had hit them hard. This is most likely because it was omnipresent and therefore a constant reminder of their limitations. Being unable to remember, particularly familiar things, was very distressing for them. However, they often covered up their distress by using humour when describing these experiences to the interviewer. There was also a sense that despite being aware of their limitations, they also fostered a sense of optimism that they would regain skills and somehow overcome it. These parallel processes of realism and optimism did not appear to be conscious, but perhaps a measure of optimism helps keep the depressive tendencies of realism at bay.

5.1.1.2 Loss of ability in social situations

Loss of ability in social situations tended to be linked to a loss of confidence as a result of memory problems. Some people with dementia noticed a change in social situations due to worries over making a fool of themselves in front of others.

PWD 6: It is um, sort of weird, I start saying something that I didn't really mean to say, you know, I'm trying sort of, this is why I talk a bit slowly (chuckles)...once I twig on that I've said something silly to em...it just makes it worse.

PWD sensed that they were losing control over what they were saying, however, it was not always something that they were aware of while it was happening. As suggested in the quote above, people with dementia often only realised they had made a faux pas by gauging the reactions of the people they were talking to. For most, this induced a loss of confidence in social situations and began to have an impact as they described withdrawing and socialising less with a smaller and (perhaps more importantly), trusted circle of family and friends.

PWD 3: We don't go out very often in the evening. We go out together shopping somewhere during the day, you feel safer see.

There was also a sense that they were now different because of their dementia, and that friends and acquaintances reacted differently to them. This had taken some getting used to.

PWD 9: ...it sometimes gets annoying when say people from down the road will come in, you know and they look at me as though you're some sort of nutcase or you know (chuckles) or they don't understand what it's about, you know that can be a

bit, a bit you know, after sort of a few months of it, I sort of just let it go over my head. (pause) I'm used to it.

This theme charts the loss of ability that people with dementia had experienced in social situations. Most were aware that their dementia sometimes caused them to make mistakes, and often they perceived that friends and acquaintances reacted differently to them since they had been diagnosed with dementia. This meant that social situations were often met with anxiety which in turn caused the people with dementia to socialise less and only with certain people where possible.

5.1.2 Identity

It has been suggested that dementia can change an individual's 'personhood' (Kitwood, 1998). Therefore, PWD were asked to describe themselves, their achievements and their relationships in order to ascertain whether they felt that their identity or 'personhood' was threatened or altered without referring directly to dementia. Within this theme PWD discussed initial reactions to diagnosis, acknowledged some changes to their temperament and also considered whether they felt their identity had endured despite dementia.

5.1.2.1. Initial reactions to diagnosis

It was part of the inclusion criteria that the PWD were aware that they had a memory problem and were happy to talk about it, so it is not surprising that they did just that. What may be surprising is that despite being referred to a 'Memory Clinic' and recognising that they had been having problems with their memory; the diagnosis of dementia still came as a shock to several of the PWD.

PWD 7: Well, I couldn't believe it you know, because, um I couldn't think, that I, I forgot things, but obviously...

PWD 8: I didn't even think of the word Alzheimer's, it never even entered my head.

PWD 2: I didn't think I was that bad (laughs), at the time. I suppose you're not, you know, somebody else sees it different.

After the immediate shock of the diagnosis PWD said that they felt depressed and very upset.

Interviewer: Do you remember how you felt at that time?

PWD 12: Yeah I cried. I did cry a lot...I can honestly say I would sometimes cry and say "oh please God take me". And that's a wicked thing and I'd say to myself "oh don't be ridiculous" you know, [daughter] and [husband], but I couldn't cope. But I could cry now just at the thought of it.

The sense of sadness at their diagnosis continued even months after they had received the news. Two other PWD described their problems as being inside their heads, whereas everything outside their heads was alright.

PWD 6: What really worries me (chuckles) it's not whether it's in the house, it's within the head. That's a lot of my worry is. Outside of my head, everything's alright.

PWD 10: You can't control what goes on in your head can you? That's the problem isn't it? You know, it's lovely if you could say "no I've got to think about that". To be able to shut the door and say... you know, just carry on normal, you know. But it just can't be done can it?

These quotes illustrate how several PWD reported feeling a lack of control over what was happening because they felt there was nothing they could do about it. As a result they described a sense of helplessness in not being able to control what was inside their own heads.

However, PWD 8, who had noticed something was not right with his memory, found that being diagnosed enabled him to cope with the problems he had noticed, rather than trying to cover them up.

*PWD 8: I realised that sometimes, the things used to go blank. Now, for somebody who can talk, and lecture, and was trained to talk and lecture...I started realising then that there was something a little bit wrong and this was many, this was going back, ooh, how many years ago was this?, going back five, six years ago...But I did tell the doc, *** (wife) and *** (wife) told the doctor, went to the doctor and of course, he sent me up here. And I've never looked back because now I realise all these things, so you know what's going wrong...So instead of trying to cover up, like if I go blank now with you for instance, I can easily cover up by just by changing the subject. But now I don't, I'd sooner sit there and think to myself where was I up to? you know, to try and bring it back again to the fore.*

Therefore, rather than experiencing helplessness and a lack of control, the diagnosis provided this PWD with a rational explanation for his worrying experiences. This conversely enabled him to feel that he could take some control and face up to the difficulties he was having rather than try to cover them up. It is inevitable that he will become less able to bring information 'to the fore' as the disease progresses, but this quote does show that being armed with a diagnosis enabled this PWD to enlist strategies and as a result develop a fighting spirit.

5.1.2.2 Change in temperament

Some of the PWD had noticed negative changes in their temperament, such as becoming less patient or more argumentative. One felt he had become grumpier, and he found this unsettling since he would never have considered himself to be a grumpy person. Therefore, people with dementia seemed to

experience a mismatch between who they saw themselves being and who they were now.

PWD 8 So I lose my temper and become grumpy. Now I'm not a grumpy person, never have been a grumpy person...

He attributed this change and others to the impact of Alzheimer's disease and accepted that such changes were a result of his problem and were not caused by him per se.

PWD 8: I think if I do change then, then it will be, only because of the, the Alzheimer's itself has changed me... not me changing.

The process by which this person with dementia separated his core identity from his Alzheimer's enabled him to cope with the changes he noticed. Although, the net effect of changes associated with Alzheimer's is a change in who he is, perhaps it is easier to stomach if changes are attributed to a side effect of Alzheimer's rather than a change in himself per se. Similarly, the quote below illustrates how another person with dementia thought she had become more argumentative due to her Alzheimer's.

PWD 12: I started when I got the Alzheimer's, answering back where I was never... I used to keep my mouth shut all the time...[now] if I think I'm right, I'm right.

Changes in temperament such as these were noted by several PWD. Although they often recognised that the changes were negative and sometimes difficult for their spouses to cope with, PWD also recognised that they were unable to stop them occurring. The concern felt by PWD with regards to these changes was somewhat abated by the view that these changes were attributable to dementia.

5.1.2.3. Enduring identity

Some PWD still felt a sense of their enduring identity despite having dementia but their identity was less well defined. Thus, people with dementia tended to list elements of their identity which they felt remained constant:

PWD 3: I'll always be (full name) anyhow, yeah meself (pause)

PWD 8: I'm still a Liverpudlian, I still talk a lot...You know, I haven't changed an awful lot, I don't think so anyway.

Interviewer: So you still feel you're like you?

PWD 6: Sort of, well, more or less in spirit, yeah sure, but I'm, we're all about somewhere.

Some PWD felt that because they could no longer engage in the activities they used to, they were no longer like themselves anymore.

PWD 10: I'm older now... I'd still like to do a day job. You know. But you can't do it really, I haven't got the energy really to do it for 7/8 hours a day and 5 days a week and... I suppose it's just getting older...I do miss them [darts and the pub] but it's a different life now you know and... I used to love darts, I did. I was quite good at them if I do say so myself, but I threw all my trophies away when we moved here, we didn't have any room for them... We had loads and loads and loads of them. That was a different life then.

Thus there was a sense of regret and a wishing for what once was, which is illustrated by pride in the level of previous expertise along with sadness for their old – and different - way of life.

5.1.3 Relationship

In a project concerning the impact of mild dementia on couples it is perhaps unsurprising that one of the themes to emerge from the analysis concerns that relationship. Indeed, the people with dementia were told of the title of the project and asked questions about their relationship with their spouse. However, the eagerness with which they talked about their spouse illustrated how important that relationship is. Three themes emerged within the relationship theme: role change, communication and being a burden.

5.1.3.1 Role Change

Several PWD commented on the change in roles that had taken place within their households, which usually centred on them doing less or at least passing responsibility onto their spouses. Often their spouses encouraged them to be involved with chores, and helped them where necessary in order for this to happen. The following quote shows an almost paternal response from Carer 7 towards his wife, which she perceived as supportive and encouraging.

*PWD 7: Sometimes I do [think my role in the household has changed] yes, and he, er *** (husband) says to me "Don't worry about it", he says "You, you do what you can and if, if you're not sure, you come and ask me" you know.*

One PWD reflected on the changes in her household and justified not doing as much because she was older and found chores more tiring than previously. This hints at denial in that she did not attribute the changes she had encountered to her dementia, but instead to the ageing process.

PWD 12: I'll... even do the ironing occasionally, but when you get to my age you don't iron as much as what you used to... I like cooking, but I'm going off the idea now, but I used to do a lot of cooking.

Some PWD admitted not being happy about the changes that had taken place. The way in which their spouses' behaviour towards them was perceived to have changed was a particular issue:

*PWD 1: I'd like to, I'd like to be able to take *** (wife) out more than what I do, at the moment, I think that she's, she's throwing a um, a sort of protective shield around me, if you like.*

Alternatively, the quote below illustrates that despite no changes in behaviour, some PWD experienced a change in their own attitudes towards how their spouse behaved towards them. This person with dementia thought nothing of his wife doing everything for him throughout his life, but now he had dementia, he saw it as a comment on his declining ability. Such changes in attitudes and behaviours sometimes proved difficult for couples to navigate.

PWD 8: ...she does everything for me you know, and really speaking she shouldn't, you know...I'll go into the bathroom and I'll come out and she's laid out my trousers and everything on the bed. Which she's always done, but now I feel it, you know?

Another PWD described how she felt that her husband sometimes found it difficult when she forgot things because during their lives she was always the one that remembered.

PWD 12: ...years ago when we had the business I was with him all the time sort of on (par), but... and it is a little bit... it's got to be frustrating for him sometimes when I do forget things... he has to do a lot more things than I... I used to be sort of in charge before, but now he's in charge.

Thus, dementia forces changes on both members of a couple whereby as one partner's ability to undertake established roles diminishes, the pressure on the

other partner to take on extra roles increases. The person with dementia may not realise the impact this has on their spouse, or they may be all too aware of their lessening ability and find it difficult to accept their partner's attempts to take on their former roles.

5.1.3.2 Communication

Communication between spouses was discussed for both its merits and difficulties. Often the person with dementia's husband or wife was the only person they would come into contact with on a regular basis, and therefore the quality of that communication appeared to have an impact on how happy the PWD perceived themselves to be. Several PWD said they felt happy to discuss anything with their spouse and were content with the communication between them.

PWD 7: Anything, anything. I can tell him anything, you know, and he's marvellous. Yeah, we never keep anything from one another, neither of us.

Another PWD felt that there was no need to discuss her memory problems with her husband because he knew her so well she didn't have to say anything. She felt this nonverbal understanding between them had contributed to her ability to cope with her situation.

PWD 11: Yes there's not much point in talking about it really because he knows... he knows me so well... and he doesn't get annoyed when I come in and say "What time are we going?" for about the third time. So perhaps if he wasn't like that I would have more problems.

However, this has the potential to prove problematic as it means that she assumes that just because her husband knows her well, he automatically knows what she is thinking. Perhaps this method of communication has limited

value, particularly as the disease progresses and both partners will experience new difficulties associated with that.

Other PWD spoke about communication problems that they had encountered such as the decline in spontaneous conversation between them and their spouse, and that the conversations they did have had become part of their routine and any spontaneity had diminished. For example, one PWD highlighted an incidence of what he saw as his wife's probably unintentional but yet insensitive approach to talking to him. This outlines his understanding of the condition and also shows his keenness to solve problems associated with it.

*PWD 8: ***'s (wife's) very patient and can understand things and we've sat and talked. I've explained to her things like "I told you that" and I'll say "*** (wife), try and use other words than I told you that. Can't you say to me, didn't I tell you that? so you're asking me the question.*

Thus, while this PWD's wife had probably given him the information concerned, he was able to explain to her that using certain phrases like 'I told you that' were disempowering for him. Between them they were able to come up with phrases that were less hurtful and therefore acceptable to him. This seemed to ease the general atmosphere between them and meant that he felt that they were tackling his dementia together.

Other PWD had noticed changes to their own communication patterns. For example, one PWD talked about having disagreements with his wife and said that rather than argue the point, he had recently tended to stand down.

PWD 1: Just lately there are times when it comes to, shall we say a disagreement um but out of all that um, rather than it being an issue, you know a continuous issue...I would tend to stand down

A tendency to stand down may also reflect the lack of confidence that the people with dementia cited in response to their mind going blank and struggling to find words. Perhaps by standing down, they can avoid being confronted by the difficulties they encounter when communicating. This therefore, would be another example of how PWD withdraw into themselves when communication between them and their spouse is affected by their dementia.

Another PWD described what he termed a 'barrier' to conversation with his wife. He attributed this to old age since they never used to have any problem when they were younger when there were always things to discuss. That the 'barrier' may be linked to changes associated with dementia does not appear to have occurred to him. However, this may be because it is difficult to disentangle the changes that would happen naturally in old age from changes caused by dementia. Indeed, leading a less busy life, as demonstrated in the quote below, may certainly be a plausible reason for having less to talk about.

PWD 3: Oh we do sometimes, we discuss things like this and um some, sometimes there's um er a barrier between us, we can't make conversation together like we usually do. Perhaps put it down to old age because um er normally we used to have a great time together, you know conversation and all that talking about different ideas and different holidays "When we going on holiday?" and all this...but sometimes we'll have a period of silence, we won't speak to each other (laughs) for, I don't know why.

Interviewer: Not angry with each other?

PWD 3: We're not, we've not had, we've not had an argument or anything, it's just, it's just as though somebody had put a shutter down.

As the section on Loss showed, people with dementia had often reduced their socialising in response to their memory problems. Here we see a further implication of decreasing social circles in that couples may have less to talk

about, which makes communication less fluent and therefore more difficult. This is where some of the people with dementia talked about a barrier between them and their spouse, which carries with it a sense of isolation. The following quotes also acknowledge difficulty with conversation and a resultant sense of isolation.

*PWD 8: I mean in the house, *** (wife) sleeps on her, sits on her side of the table and I sit on my side and we've sort of, sort of got our own lives, you know.*

PWD 3: But being stuck in the house all the time and watching that (pause) bloody box (chuckles). I reckon if we could get out more, (pause) conversation would be well efficient, I think.

This sense of isolation and loneliness persisted despite the fact that most of the couples did almost everything together. This again highlights that the people with dementia felt trapped as a result of a shrinking social circle, fear of going out and a general loss of confidence in response to the memory problems they experienced.

Communication was certainly awkward for PWD due to dementia associated problems such as remembering what they wanted to say. Within their relationship with their spouse, some PWD described further difficulties such as insensitive comments and feeling as though a 'barrier' or 'shield' existed between them. The trouble PWD had with communication, particularly when this affected communication with their spouse, led to feelings of isolation and loneliness.

5.1.3.3 Being a burden

Whilst most PWD said that they felt able to discuss anything with their spouse, a number of them were nonetheless reluctant to discuss their worries with their spouse because they felt that their spouse 'had enough on their plate'. This

unwillingness to discuss things was sometimes related to the person with dementia feeling like a burden.

PWD 2: Yeah. She's got enough problems of her own...without me as well, I'm a burden.

PWD 11: I do wish I didn't need to have to go and ask him again, but... as I think he must get fed up with it.

PWD were all grateful for the support given to them by their spouses, and they were all aware that their spouses did what they considered to be more than their fair share in the household.

PWD 2: Well she does it because there's nobody else to do it (laughs)

This quote illustrates that PWD were aware that their spouses cared for them at least in part because there was no-one else to do it. This did not mean that they felt that their spouses did not want to care for them, but it does illustrate a sense of awareness among PWD. Further to this, some PWD said that they made the effort to do things for themselves so that they wouldn't have to ask their spouses so often.

*PWD 5: Yes. I try not to ask *** (husband) too much. I try to look at the calendar first so that I know what's happening.*

Interviewer: OK. And why do you try not to ask him?

PWD 5: Well he's got enough on his plate without me, I mean, without worrying, you know, if I can remember and do it and go there. Well he will remind me too, he'll say don't forget we're going so and so or something like that, or today, you were coming today.

This suggests that the PWD realised that caring for someone with dementia is not an easy task. They often talked about trying to work things out for

themselves before asking their spouse, and were eager not to inconvenience them. With this comes a sense that the PWD did not want their situation to be any harder than it had to be, and while they had noticed changes, they tried to keep the impact of these changes to a minimum. However, despite these efforts, some PWD felt that they were a burden to their spouses in part because they recognised that their spouses cared for them because there was no-one else to do it. The issue of burden seemed to be rather taboo for none of the PWD that talked about it in the interviews reported discussing these issues with their spouse.

5.2 Coping

An individual's ability to cope is utilised everyday to deal with all demands from the very minor to more significant difficulties associated with having dementia. PWD spoke about the process of acceptance and coming to terms with their diagnosis, as well as more practical coping strategies they had employed, which make up the two themes of this section. The "acceptance" theme explores the process of acceptance that PWD went through as a means of coping successfully with dementia. Secondly, the "aids to coping" theme demonstrates the techniques employed by PWD to help them get over both the everyday difficulties associated with dementia and also to help them achieve a level of understanding and finally acceptance.

5.2.1. Process of acceptance

For any change experienced, there is a process of acceptance and adaptation that individuals go through in order to assimilate that change into their existing person and situation. Whether this process advances effortlessly or is strewn with difficulties rather depends both on the change in question, and to some extent on the person. The process of acceptance of a dementia diagnosis is outlined as PWD described how they have attempted to explain dementia both to themselves and others as well as how they have altered their cognitions in order to maintain control of the impact dementia had on their lives.

5.2.1.1. Attempts to explain

Following the diagnosis of dementia, PWD said they started to question how this had happened to them.

PWD 1: Oh, I was quite amazed, I, you know, I thought, how on earth did this happen, what's caused it you know to, for this to happen.

PWD 3: How did, how did I um, how did I come by it? I wouldn't've thought that it could happen to me. But there you are. It does dun't it.

In addition to thinking about *how* it happened, most PWD also admitted asking themselves *why* it had happened, and in particular, why it had to happen to them.

PWD 4: I used to sit here crying me bloody eyes out (short pause) because why did it happen to me.

PWD 7: Well yes, yes, yes and I think 'Why me?'...(crying) I often think "Why me?".

Some PWD explained their diagnosis in terms of genetics: Alzheimer's was in their family, which provided a way of explaining why they had developed the disease.

PWD 5: I suppose, (pause) because it does run in the family, my sister and I were talking about it many many years ago and we both said the odds were that one if not both of us would have memory problems because there were memory problems on both sides of the family.

Other PWD thought that the reason they had got dementia might be due to earlier events in their lives. One person with dementia highlighted that he had had a tendency to forget all throughout his lifetime. Another blamed her career as a secretary for meaning that she had got into the habit of not needing to remember things because she had simply noted them down as part of her job.

PWD 5: I think that's because having been a secretary you, you know yourself, you automatically write everything down.

While, another person with dementia said that her memory problems developed when she retired following a busy hard-working life.

PWD 12: When you've had a busy life and you go out most days and you're doing things and that sort of thing, all of a sudden you're stuck at home all the time...

Thus, PWD provided a variety of explanations for the onset of their dementia as they searched for understanding as to why it had happened to them. At present the reason why dementia afflicts some people and not others is not well understood, so it is not surprising that PWD seek their own explanations.

PWD 8: ...it is an age thing and as I get older, you expect to, to, to lose a little bit of your faculties.

The process of searching for reasons seemed to help PWD provide an explanation or logical narrative that fits in with their view of the world, which also somehow normalises it. Indeed, PWD were keen to ask themselves why this had happened to them, and to find a plausible answer. Often they were aware that the conclusion they had come to may not be correct, but nonetheless it helped to have a conclusion. None of them said that they blamed themselves per se, but rather things that had happened to them or certain paths they had chosen. Whether this is thought of as blame or excuses or reasons, they arguably all help the person with dementia to understand what is happening to them. It seems that reaching a certain level of

understanding is a necessary precursor to beginning their journey towards acceptance, which starts with people questioning their situation and developing theories as to why it has happened to them.

5.2.1.2. Reactions to day to day issues

Some PWD continued to feel shocked and depressed for some time following their diagnosis. This was usually linked to the memory and functional problems they had to deal with, and despite the best intentions and generally coping very well, PWD did experience times when they felt depressed, frustrated and/or angry about their situations.

PWD 9: Sometimes it sort of gets you down...Some, some days I you know, you, you can feel a bit down.

PWD 10 also found that he felt depressed about his situation because he was unable to stop thinking about it and had seen other family members deteriorate before him.

PWD 10: I suppose it has [impacted my life] in some... I suppose a bit mentally it has because you can't get it out your mind, it's not something you can get out of your mind... You try to forget about it but you can't forget, it's not something you forget. You've seen what's gone on before you as well [with other family members] it's.... you know, it's... it can be depressing and I suppose maybe that's why I do get a bit depressed now and then you know.

The knowledge of his condition was further compounded by having seen the impact on other family members. This person therefore had insight into what might lie ahead, which made it harder for him to cope with.

Several PWD reported feeling annoyed at their situations or with their memory problems and the difficulties they endured on a day to day basis.

PWD 3: I'm alright, it's just that um er, now and again I feel that um, this loss of memory, it annoys me sometimes to think that, now that it's a part of me.

PWD 11: ...emotionally you're irritated because you know you've had to go and ask again because you've forgotten... you're bad tempered about it because you don't like being, I don't like being like this and I hate it when I have to repeat myself, and when he says "you've just told me that" I could kick myself.

PWD felt hatred towards this uninvited disease that had become part of them but was also taking things away from them. This engendered deep feelings of anger and frustration directed towards the dementia, and also how they saw themselves now. Again, quotes such as "I don't like being like this" illustrate a huge sense of lack of control and that dementia has changed who they are. These quotes illustrate how these PWD saw an inescapable aspect to their situation. While they tried their best to carry on and live with it, it is understandable that at times they felt unhappy about it.

Attempts to explain the diagnosis and reactions to day to day issues have shown how PWD changed how they felt about having dementia from first suspecting it, to being diagnosed, to learning to live with it. For several PWD, the diagnosis of dementia was met with fear, shock and surprise. However, when the PWD were interviewed for this project, their feelings towards their situation had moved on somewhat from that initial reaction. Some experienced feelings of depression or worried what the future would hold, but nonetheless, all PWD had developed ways of coping with their situation that allowed them to continue functioning in everyday life. Furthermore, the fact that they were able to describe their feelings towards their diagnosis and the day to day issues it brought, suggests that they had a level of awareness about what was happening to them. The following section will address awareness and its implications for acceptance.

5.2.1.3. Awareness

In order to come to terms with something, one must first be aware of it. Differing levels of awareness may represent simply knowing the labels attached to an illness, to having a greater understanding of what these labels might mean.

A number of PWD used the word 'Alzheimer's' or 'dementia' which illustrates an awareness of the terminology surrounding their diagnosis. However, other PWD were less explicit in their descriptions of their difficulties and referred instead to more generic memory loss or getting muddled.

PWD 3: Yeah, I'm alright. I think that um er, I'm aware now, more aware that er I am getting um, the old memory loss. Not um, er, how shall I put it? Not bad mind, we'll put it that way, not bad, but I know I've got it there as regards forgetting things.

The tendency to use softer terms such as 'old memory loss' perhaps indicates a lack of understanding of the implications of their diagnosis, or alternatively a desire to downplay its significance.

As well as being aware of their present situation, several PWD also showed an appreciation for the future. This again indicates an awareness and an understanding of their diagnosis.

PWD 1: You know, I realise now that I, it's not gonna come back to me [the ability to write].

PWD 4: It's not gonna get any better.

PWD 10: I've been thinking about, been thinking about how much time I'm gonna have where I'm gonna be like I am now.

Other PWD were not so sure what to expect. The quote below shows that whilst this person with dementia had thought about the future, there seemed to be a lack of understanding about his diagnosis because arguably the best time to make the plans he talked about would have been then while his Alzheimer's Disease was mild and he was able to make the decision.

PWD 1: Well, I've thought about the future, (pause) I thought, you know, what is gonna be the, the result of all of this, if it all goes wrong. I thought, is it gonna kill me? Um, if it is, um, you know, I would have to make, um, plans. Um, in the end of the happening, I would have to make, um, probably changes in life.

All PWD were aware that they had some problems with their memory and for the main, they were aware that these problems were as the result of their dementia. Secondly, PWD also showed some awareness of the prognosis for the future.

5.2.1.4. Reaching Acceptance

Most PWD seemed to describe a level of acceptance that they had dementia, although this was reflected in two different ways. Firstly and more overwhelmingly was the feeling that they couldn't do anything about their situation so they had no choice but to get on with things. Secondly, there was a sense of contentment among PWD: that they were happy with their lives despite having dementia. The latter was represented in a significant minority of PWD in this project. Perhaps the second stage represents the final stage of true acceptance, but accepting that there is no choice seemed to be an essential thought process in order for the PWD to move towards being happy with their situation.

Several PWD expressed the view that there was nothing they could do about the fact they had dementia. In some cases, this meant that they felt that they

had no choice but to accept it. Some PWD described approaching life as it came and dealing with things in a matter of fact manner.

PWD 8: I tend to take things, if that's what it is, that's what it is, you know, if I'd been born with one leg, I'd've been born with one leg.

PWD 6: Well, in my mind, there's nothing I can do about it, so it doesn't matter. I've got used to it.

PWD 5: Um, but it's, unfortunately it's not something that one can do anything about. You can't make yourself remember, you either do or you don't. (laughs) you know, if there was something I could do, I would do it! (laughs)...I mean it isn't something that you can, unfortunately, that you can make yourself do. I mean you can try your hardest to remember but you can't make yourself remember if your brain says no I'm not gonna remember that.

The recognition that there was nothing they could do about their diagnosis led some PWD to feel they could do nothing but accept it.

PWD 3 You'll not, you'll not be able to have anything done to it really, it's just one of those things you've got to accept.

PWD 8: I know there's no actual, you can't take medicine and it'll make you better, and if this is what it is, this is what we're gonna have to live with. So, I accepted it as it is.

PWD 2: But, you've just gotta accept it, haven't you, can't do nothing about it...don't get to you too much because you know you can't do anything about it.

Having accepted the diagnosis, some PWD expressed contentment with their lives. When describing contentment, they often talked about good memories of their lives on which to reflect, as this seemed to be linked to the PWD's ability to think positively of the future and foster a keenness to make the most of their time left.

PWD 8: It's only an ageing thing anyway, you know, you're gonna get old and you're gonna get a bit potty eventually, so, be potty and happy!...So if here I am with Alzheimer's, I'm quite happy that I got here.

PWD 9: I don't feel sorry for myself you know, cos as I said I've had a very, done a lot... So, I'm happy (laughs).

PWD 4: I've had a good life, let's make good use of the rest of it, make good of the rest of it.

Reaching contentment seemed to be an active process, and one which PWD had to work at by reminding themselves to focus on the positive aspects. PWD also strongly associated being content with their life presently with having lived a good and full life. Interestingly, not all PWD who did report a good and full life also reported feeling content at the time of the interviews. Therefore, perhaps this suggests that some level of evaluation is necessary to merge to two parts of their lives? Nonetheless, most PWD claimed some level of acceptance of their diagnosis and what it meant for them. It is possible that individuals must recognise that they cannot change the fact that they have dementia, before they can be content with what they do have.

5.2.1.5. Maintaining control

Despite feeling depressed, frustrated and annoyed about having dementia, all of the PWD also demonstrated an emotional positivity towards their situation. It seemed that they needed to think positively in order to maintain control of their dementia and its effects upon their lives. All PWD showed some evidence of

positive thinking and most spoke specifically of the need to think positively about their situation. This fell into two categories of mind over matter and optimism, which will each now be discussed.

For some PWD, the idea of mind over matter meant that they tried not to dwell on their situation or ruminate about what might happen in the future. This was not denial per se because they demonstrated an awareness of their problems but also tried not to let it get to them.

One person with dementia illustrated this by stating that although she is aware that she quickly forgets things, it isn't constantly on her mind. She thought that if she did worry all the time about the things she forgot she would feel under pressure and be less likely to be able to cope with it.

PWD 5: Yes. Yeah, yes. Well I don't consciously get up and think now what have I got to remember today? (laughs) You know, I come down and look at the calendar and then I, you know, um work from there. (laughs) I think you'd drive yourself mad if you kept.

Interviewer: It's more pressure isn't it I suppose

PWD 5: Yes, I think, I think, I think it would be worse. If you sort of got up and thought "What have I got to remember today?" I don't think I could cope with that! (laughs).

Other PWD talked about 'taking things as they come'. They acknowledged that sometimes things went their way and sometimes they didn't, but also they accepted that this was the case.

PWD 3: Well I, I can't put my finger on it on one individual day, I um, you know, I just take it as it comes, but I don't think that um whether it's a Monday, Tuesday or Wednesday or Thursday. It's just one of those days, you might get up and things go wrong! (laughs)

Others talked about attempts to actively block or forget the situation.

PWD 6: Now that, well, I know it's there, and, and, things like that, but I just pass it by, yeah. I, if I dwell on it, it's gonna get worse. If I, I, push it away, then it's not gonna, isn't gonna be there.

PWD 8: I like to forget the Alzheimer's, things sort of, not to worry about there, I can't do much about it.

Mind over matter includes both the PWD who do not want to ruminate about their problems and also those who attempt to forget about them as much as they can. The PWD all felt that these measures were helping them to deal with the fact that they had dementia. While attempts to forget could be construed as attempts to deny what is happening, they could equally be thought of as attempts to concentrate on the good things in life.

Overwhelmingly, PWD showed they felt optimism towards their situation. This was demonstrated by how PWD described their coping strategies, as well as their general approach to life. PWD frequently described feeling that their situation could be worse. They did this by comparing themselves to others in the same situation and also by thinking of other ailments or situations that would be worse than the one they were faced with. When talking about others they knew who also had dementia, a number of PWD commented that the problems others exhibited seemed more severe than their own. However, they did not acknowledge that inevitably they would also deteriorate in the future.

PWD 10: I feel sorry for him because he's a lot worse than I am and he's a hell of a lot younger than I am. And he's a very, very well educated guy.

PWD 6: In my mind, I'm better off than one of my, my friends, and he got a terrible stutter...Because he can't think what he's

saying, and I am better in that way, I do know what I'm talking about, but he stutters all the time.

These quotes illustrate how PWD made comparisons with others, and in doing so inferred ways in which they were better off than others. The first quote is interesting since it implies that dementia is worse for someone who is younger and well educated. The reference to his friend being well educated indicates that PWD 10 felt that his friend had more to lose. This last quote is an interesting interpretation by the PWD of his friend who stutters. In fact people who stutter know what they want to say but struggle to express it, so this PWD is mistaken to think "he can't think what he's saying". Furthermore, dementia causes people to forget what they want to say, and even how to say it, which this person with dementia reported earlier had affected his confidence in social circles. Therefore, these PWD found it useful to compare their problems with other people's in order to provide some perspective and help them to cope with their own difficulties.

Other PWD demonstrated their optimistic outlook by declaring themselves 'lucky'.

PWD 8: I mean er, I honestly believe, I honestly think that I'm lucky. Opposed to unlucky...and little things to me, like Alzheimer's is nothing by comparison of the worry of my sister dying...I don't know what you want to hear me saying, or, or what, but I, I don't feel bad about it all, you know, I mean, I could have had yellow fever or something couldn't I, you know... there's always something worse, you know.

This PWD also pointed out that people without dementia can have bad memories, so it is not only them who struggle with their memory.

PWD 8: I think people without Alzheimer's can have bad memories.

This may help PWD by emphasising that they are not alone in their memory struggle, although equating Alzheimer's to having a bad memory very much downplays the longer term consequences and implications of dementia. Some PWD tried to put dementia into context by trivialising the impact of dementia as a trick or just a part of getting old, and insisting that they simply had to live with it. On the whole, PWD were keen to get on with their lives and not let dementia take over.

PWD 3: Like everything else, the old memory plays very funny tricks on you.

PWD 4: All I've gotta do is live with it.

PWD 8: So I tend to just say Alzheimer's myzels who, who cares? You know, get on with your life...we've still got a lotta living to do, so with that in mind, you might think oh well you're making too big a thing of that. It's not, it's not making a big thing of going to see these things. It's, not giving in. You know, not saying oh well I might as well sit here and... stroke the dog or whatever, I'm not gonna sit here and stroke the bloody dog! (laughs).

Perhaps having such a positive attitude to the impact of dementia on their lives means that the goal of getting on with their lives is more attainable. Among all PWD was a sense that they were doing their best, attempting to continue with life as best they could.

PWD 12: I think you've got to have... get yourself going and... you do... you can fight things if you get up and going. You've got to.

PWD 5: I don't like it, but I'll be quite honest I don't. Drives me mad at times, but I do my best to combat it, but doing my crosswords, by going out, by trying to keep my brain active.

Some PWD commented on their anti-dementia medication and the belief they held that it was doing them good. They recognised that by taking their medication correctly, they were helping themselves as much as they could.

PWD 1: When I take my pills I think to myself (whispers) I'm getting better, you're making me better and I believe in you.

Interviewer: And that helps?

PWD 1: I think believing in what you're doing, yes you're right.

PWD 12: Once I started taking those tablets I came alive again, and if anybody disputes that and says them tablets are not worth it, for somebody that's got Alzheimer's they want to have Alzheimer's themselves to find out what it's like. I'm ever so strong about that.

Interviewer: Ok, so the tablets have given you a life line?

PWD 12: A new life. A new life. I came alive again. Alright I won't go out on my own and I'm always with somebody because I'm afraid of feeling like when it first started, I went to walk around a corner and didn't know where I was. I will never ever go out on my own, but I'll go nearly anywhere now because it brought me... well it did bring me back alive and if ever anybody wants proof of that well I can tell them.

These two quotes demonstrate the faith and hope that PWD put into the medication. It also shows how important individuals' perceptions are. For example, PWD 12 felt as though she came back to life when she started her medication. At the time of the interviews, she no longer had any independence but still felt better in herself than in the pre-medication period leading up to her diagnosis.

PWD also demonstrated a fighting spirit which meant they were keen not to let things get the better of them. In the following quotes PWD describe actively

fighting against dementia, and again the importance of believing that their efforts will help.

PWD 5: Um, but I deliberately do them [crosswords] these days in an effort to keep my brain active...It is my way of trying to fight back a bit (laughs)

PWD 1: I've got to beat this, you know, this is my enemy um, and I don't, my enemy beats me or I beat the enemy. And I don't want to be beaten. That's my feeling about it and I'm, I, I've just got this feeling that I'm possibly can get over this...I know that my age is against me, but at the same time I feel that I could, beat this.

Perhaps the idea that PWD 1 can beat it is misleading but maybe that isn't important. Rather it could be the belief in himself that allows him to cope with feeling down about his situation.

Maintaining control encompasses the idea of positive thinking, and also the idea that PWD tried to put their situation into perspective in order improve their ability to cope with it. This was often despite feelings of depression or frustration that PWD felt about their situation, and some PWD felt more positive than others and each person with dementia had experienced times when they felt more positive than at other times. However, all of the PWD wanted to make the best of things which is indicative of both their enthusiasm for survival and their refusal to give in.

5.2.2 Aids to coping

The theme of Aids to Coping showcases the concrete ways in which participants described attempting to cope with dementia and its associated problems. The coping strategies employed included mental and physical exercise undertaken by PWD in order to keep them alert and active. In addition, all PWD were keen to talk about their achievements and good

memories and it became clear that being able to recognise their achievements meant a lot of them, particularly at a time when they felt less secure about their future. Thirdly, PWD often attempted to maintain some independence either with chores they were used to performing or by devising ways to go out alone yet safely. Finally, PWD often spoke of the importance of their support network, which included everyone from their spouse to their children to their neighbours, and how these relationships helped them to cope.

5.2.2.1. Mental and physical activity

As the title suggests this sub-theme includes both mental and physical exercise, both of which PWD were keen to persevere with.

Several PWD talked about keeping their brain active by doing puzzles or crosswords. They hoped that by keeping their brains active in this way they were doing the best they could to counter the effects of dementia and improve their concentration.

PWD 5: I always thought that it [dementia] could [happen], I was hoping it wouldn't! (laughs) But, the fact that it did, it's, I do my best to counteract it, by doing my crosswords and trying to keep my brain active.

Mental activity was also upheld because it represented something that the PWD could still do. For one person with dementia, reading was a source of calmness.

PWD 6: When I do read a book I can still remember what some of it is. When I, when I put it away...It [reading] certainly cools me down a bit.

Other PWD reported using tricks to try and remember things, such as people's names or the way to the shops.

PWD 8: So I use this, um I don't think they're tricks, I think they're, they're aids, you know to make sure that I can remember, things...It's not, it's not something to be ashamed of because you're, you're using some aid, you know.

There did seem to be some issue surrounding the use of the word 'trick', perhaps because of its negative connotations with deception. Indeed, this person with dementia seemed happier when he described using 'aids' as opposed to 'tricks'. However, does highlighting that using aids was nothing to be ashamed of suggest that he felt some discomfort at having to rely on external aids? This sentence feels as though he is trying to convince himself, especially with the use of 'some aid' as though the aid is just some insignificant thing rather than something essential to him coping with dementia.

One person with dementia had had technological aids installed around his house following an incident when he burnt his hand on the gas cooker. He was keen to point out that he didn't need them as such, but they are more there for prevention. However, he did not acknowledge that he may need to rely on them more regularly in the future. Perhaps this is another example of downplaying the implications of dementia, whilst also being aware of the prognosis.

PWD 9: These things, really it's, you know these things are a bit isolated, what happens like that...you know, it doesn't happen every day...And I think it's more prevention.

Like the PWD who downplayed his need to use 'some aid', this is another case where the person with dementia felt a bit silly that he had made a mistake. Both of these PWD appear to feel at least a bit embarrassed by the need to rely on aids or tricks. This suggests that even though mistakes can be rationally attributed to dementia and therefore no fault of their own, people with dementia are not always so able to compartmentalise their feelings when something goes wrong.

On the whole however, engaging in mental activity was framed by PWD as being beneficial in that it gave them a sense of empowerment by allowing them to use the parts of their cognition that were inherently failing due to their dementia. Despite noticing a decline in their abilities, PWD were still keen to partake in mental activities. They were proud of the achievements they made, and even small achievements such as reading a page of a book and remembering something about it, helped them to feel they were doing what they could against the progression of dementia.

Physical activity was also important. Some PWD were eager to continue with physical activities such as travelling or keeping up with the garden. This was usually in keeping with a general sense of wanting to keep active and keep doing the things they enjoyed. The following quote is from a person with dementia who used to travel with his wife in their caravan. They really enjoyed the freedom that afforded them and he was pleased that they had managed to find a way around it since he lost his driving licence and they had to sell the car and caravan. They now go on coach trips which enables them to maintain a level of independence and spontaneity as their situation allows.

PWD 4: We're doing a coach trip, er next week, we're going down to Devon way, then we'll come back for another fortnight, three weeks, and then we're off again down there. In that direction.

A number of PWD had actively decided that as their old hobbies were no longer achievable, that they would try alternatives. Like the example above, some PWD were surprised that they enjoyed these new activities. Ultimately, their involvement in activities meant that they could remain active and enabled them to feel busy. This is a proactive method that enabled them to continue with their passions, albeit via different routes. This is an example of a positive coping strategy whereby PWD found their way around obstacles rather than being beaten by them.

PWD 12: We go to these clubs, over 60's and various things, I can't understand people that don't do it because it's a good way of... he [husband] didn't seem too keen I don't think at the first... but it is good because it's people of your own age and they have holidays and days outing... I never thought I'd ever see myself go, but really, old people are really good fun.

This quote shows that although PWD 12 was in her late 70's and therefore well over the age limit for these clubs, she did not really see herself as an 'old person'. However, despite this, she went forth enthusiastically and found that she really enjoyed the experience.

One person with dementia, whose brother had also been diagnosed with Alzheimer's and was further on with the disease, had made some observations about how his brother had coped with it which had made him keen to keep active.

PWD 10: When he retired he... he didn't do anything. I mean he was never a gardener, he was never someone who decorated the house and... you know, he just seemed to... I don't know, he just seemed to let everything go like that and things you know.

Interviewer: Right. So is that why you're keen to keep working and?

PWD 10: That's... I'm keen to keep doing something every day you know, not sit indoors all day and that you know.

PWD showed in this sub-theme that they were eager to keep both mentally and physically active. They had devised ways to maintain their levels of mental and physical activity to levels that they deemed acceptable considering their illness and the problems associated with it.

5.2.2.2. Recognising achievements

During the interviews, PWD were keen to talk about things they had done during their lives that they were proud of. Remembering back to happy times appeared to help them to cope with their present difficulties in the sense that they accepted the trade between having lived a good, happy life and now experiencing some problems.

In addition, when the PWD were having difficulty with the present, it seemed to reassure them to think back to happy times, not least to remind them that they did not always struggle in the ways they did now. In fact, remembering what they had done well seemed to be particularly therapeutic as it allowed them to focus on the positive things they had achieved even if they were feeling negatively towards their present situation at that time. A number of PWD had recently celebrated or were shortly due to celebrate ruby or golden wedding anniversaries, and they felt proud of that achievement. Some described more lively marriages than others, but all PWD expressed much love for their spouses. Others spoke of their achievements through work. Below are some examples of achievements that they described.

PWD 4: I've got forty years of my life caravanning...That's what I liked...I was going all round the country...Every where we went. All the sea-sides...We were away (pause) um, once a fortnight or three weeks, we was off. Gone. Or if it was the weekend, short, short weekend, you know, three days, goes off. Go and pick the caravan up, with a few bits in it, Tisch! Gone.

PWD 9: You'll love this one um, I was really into rock music and I, um went to audition for the Rolling Stones!...Yeah (laughs) you know, I didn't get it, or I probably wouldn't be here now...the drugs! (laughs)

PWD 8: If I'd've told you everything about my life we'd've still been there for... for weeks! (laughs) you know, there was a lot to it...And I fall back on that now...I think to myself, there's not many, too many people who have done things like that.

All of the PWD felt that they had lived interesting and eventful lives which they were keen to talk about. Some had lived through difficult times but these too seemed to be thought of positively in that they were generally pleased that they had managed to overcome them. In the main though, thinking back to happy times and achievements that they were proud of made PWD feel that they had done well with their lives. These achievements were not always glamorous but were all equally important for providing good, happy memories of past times. Feeling that they had done something worthwhile with their lives seemed to help PWD to come to terms with their dementia, particularly as they knew that their condition would not improve. On the whole, PWD were keen to partake in an appraisal of their lives. Therefore, perhaps it is a necessary step, i.e. because their future will inevitably be different to how they hoped it would be, PWD could redress the balance somewhat by focusing on the positive things they had experienced in the past.

5.2.2.3. Attempts to maintain independence

PWD talked about independence in two ways during the interviews. One way focused on a loss of independence which was described during the Loss section presented earlier in this chapter. However, PWD also mentioned independence in the context of their attempts to maintain it. They spoke often about how they had managed to adjust to dementia by instigating routines and developing a sense of responsibility as a means of maintaining independence.

PWD regularly mentioned the importance of developing routines which helped them feel more organised. This went from keeping things in certain places to keeping busy, to having specific chores for each day of the week. In general, household chores fit in well to routine and most participants were keen to retain some level of involvement with the housework. This was often

something that couples tackled together. PWD's routines were far from sedentary, and they often denoted a keenness to keep going. This suggests that they felt some responsibility for themselves and their well-being.

PWD 2: Yeah, I know where things are...But if somebody moves something it's like she's tidied it up, I can't find, I'm so used to it just going there...and it's not there anymore.

*PWD 8: I mean, my dog, well it's ***'s (wife's) dog, it's supposed to be ***'s (wife's) dog, but if it was ***'s (wife's) dog I don't know how come I take it out every, twice a day!*

PWD also liked to feel useful and took pleasure in doing things that they had been good at throughout their lives. PWD 9 had been a service engineer and now in his retirement he was always happy to fix something for someone as he had been all his life.

PWD 9: Yeah, yeah, its surprising, I thought I was gonna get bored, but there always seems to be something to do... or somebody might come round with something... cos I like actually repairing things, because that's all I've ever done all my life, you know... to do things like somebody come down and said my kettle's broke or someink like that, you know, I'm glad to do it you know.

However, not all PWD were happy with the standards they were now able to reach.

PWD 6: Sometimes I do, sometimes I do that [work in the garden]. (laughs)...But it doesn't look so good nowadays... I can cope, let's, let's put it that way. I wouldn't say I was completely on top of it because looking at that makes me think that, but um, yeah I could do what I'm supposed to do. You know, if I say "I'll do this", then I'll do it.

PWD found that while their level of ability had declined, it was difficult to then foster realistic expectations of what they could achieve. In this case, while PWD 6 was still able to garden, he did not gain as much satisfaction from it because he did not feel he was able to complete the tasks to the high standard he attained prior to dementia.

Other PWD talked about doing things in such a way that an interest and motivation for adventure was evident. In particular, PWD 3, despite the fact that he was 80, still showed an enthusiasm for joining the local gym, scuba diving and hot air ballooning – all three of which he would love to do if his wife would let him!

*PWD 3: *** (Sister-in-law) says to me, that's my sister in law, she said "When you're 80 how would you fancy going up in a hot air balloon?" I said "Cor that's great, I wouldn't mind" she said "Well we'll see if we can arrange it!" (laughs)*

Other PWD described how their spouses help them so that they can stay involved with perhaps more sedate activities. In particular, PWD 7 commented that although her husband now had responsibility for most of the household chores, he always involved her and asked her opinion.

*PWD 7: Um, well *** (husband) does everything with the money now, you know... and um, but he always er, when we go shopping um, he'll say, "What about this? If you don't like it, we won't get it" you know.*

Similarly, other PWD welcomed the practical support their spouse provided. PWD 1 considered his anti-dementia medication to be very important and knew that he could rely on his wife to remind him to take it if he forgot.

PWD 1: Not all of it, you know, er there are things that I remember but I would forget for instance, (pause) the thing

that keeps me alive is the pills...as such. Now I am likely to forget those pills... but put simply I've got a back up (his wife).

We have seen that PWD were keen to maintain skills with regard to gardening and household chores, but independence at a higher level i.e. doing things on their own, was an issue that was also discussed by some. For example, PWD 3's wife was due to be going away for a few days and I asked him how he felt about this.

PWD 3: I can look after myself. I looked after myself for twenty odd years whilst I was in the Navy.

Although initially confident he would be ok and downplaying the significance of not having his wife around, he went on to hint at some uneasiness as to what might happen when he was on his own.

PWD 3 But then I thinks to myself, you know, touch wood, you never know when you gonna collapse do ya (laughs).

It seems that this person with dementia felt a little unsure of his own physical health, and be that because of his age and/or existing condition, it does indicate that while he feels able to cope on his own, he feels more secure with his wife there. A further security measure was described by another person.

PWD 4: ...but I always carry a phone with me when I go anywhere, if I go out for a walk, cos I got one of those walking frames as well as my electric chair.

There was a sense of uneasiness and fear in these quotes highlighted by a desire for security either from their spouse's physical presence, or by knowing that they can be contacted if necessary. It seemed that their spouse being emotionally and physically available to them was important to PWD in that it allowed them to maintain an acceptable level of independence.

This theme has demonstrated that PWD felt comfortable with the introduction and/or maintenance of routines that allowed them to feel more confident in what was happening in their day to day lives. It also described the sense of responsibility that PWD were keen to foster in their activities and chores: they were often happy that spouses helped them with day to day activities but were equally pleased to have some autonomy in what they were doing. A more palpable sense of independence was also remarked on by some PWD who were proud to be on their own some times.

5.2.2.4. Importance of support network

All PWD talked about the support they received from others, primarily their husband or wife. This afforded PWD some level of security and confidence that allowed them to continue to function in their day to day lives.

The support was primarily given by their spouse but also by family members (sons, daughters, siblings) and professionals involved in their care. PWD were thankful for all the help given to them and recognised not only the tangible deeds that people did, but also the more subtle gestures bestowed upon them such as not having to face comments if they forgot something or made a mistake.

Most frequently PWD talked about the support they received from their spouse in terms of kindness and understanding. This was sometimes described as a response to dementia-specific problems, but also encompassed a more general sense of compassion that PWD felt from their spouses. They often described a sense of security, confidence and calmness that they felt when they were with their spouse.

*PWD 1: ...if I'm, you see, in her presence I'm, I'm calm...
I'm calm, relaxed and composed, um, it's er, it almost happens
when I'm not with her [that he gets anxious and shakes].*

PWD 7: Well sometimes I think you know because um if I forget where about something or where something, he'll just say to me "Now stop and think, don't worry about it, just stop and think". He'll say now calm yourself down... And then that's it, I know where it is or what, you know, where I've put it, or whatever.

As we saw in the previous theme, PWD seemed to perceive their spouses as a form of security. Here, they described how being in the presence of their spouse had a calming effect due to the fact that they understood the effects of dementia. Therefore, PWD did not feel pressurised to uphold prior social status in the same way they often did when they talked with friends and family.

Other PWD talked about the practical support they received from their spouses. This referred to helping them to remember specific things or rather helping them more generally.

PWD 4: I forgets to take 'em sometimes, "Have you taken your tablets?" I say "Oh no, I forgot about that", "You better take your tablets then", I said "Yeah OK". So I has those. What else? Um (pause) sort of thing like cooking the dinner that's all, "Dinner's ready, do you want to sit up".

Interviewer: So is it practical things then?

PWD 4: Oh yeah, yeah.

PWD 11: I can cope with cooking and all that sort of thing, but without [husband] I don't know.

There was a huge sense of reliance upon carers from some PWD. This shows that they had great faith in their spouses, and that they felt safe and secure whilst in their care. However, it also spells a great responsibility for their carers, and perhaps a pressure to live up to the ideals within which they were held.

As most participants were retired, the majority of the PWD spent most of their time with their spouse and therefore carried out various day to day activities with them. Some PWD felt that this fostered a sense of interdependence whereby being together benefited their spouse as much as it benefited them: whilst they received support from their spouses, they also gave their spouses support in return. Indeed, PWD often felt confident that their spouse preferred to be with them than doing things on their own, and in some cases, PWD felt that the presence of dementia had in fact made them closer as couples.

PWD 3: ...I gives her a helping hand sometimes, but, and I takes her a cup of tea upstairs, she retires at night, and er she'll go upstairs first and I'll stay on her back just in case that she don't overbalance...

PWD 4: Well yeah um, if she wants some help well I'll help all that sort of thing. I don't let her struggle on her own or any of that type of thing. And that's the same when she's you know, when she's doing anything. I mean I give her a hand if she wants to strip the bed off, um we make the bed and that sort of thing, I give her a hand to do that.

PWD 9: It's definitely made us closer... I think it's because we help each other... Like if I'm down she sort of gets me out of it and it doesn't happen that (often), or if she comes home and she's had a bad day or whatever.

In addition to the support received from spouses, PWD also spoke about support from their wider families, who provided mostly emotional support rather than practical help. In most cases this was because PWD had mild problems which rather than requiring practical help, instead required their families to be understanding. Families were very important to PWD. They gave them something to focus on as well as providing them with encouragement and support.

PWD 8: So the family is very, very important to us, you know, it's er it, that's our life really is the family.

Other PWD also mentioned that it was nice to feel included in people's thoughts and plans. This was particularly so as the PWD were aware that their family had busy lives themselves.

PWD 7: ...the daughter's always there, coming to see us or they'll say "Are you coming down Mum and Dad?" or whatever you know, or "Are we seeing you today?" or "What have you been doing?" They, quite, family's quite good.

It was also important that family did not point out mistakes that the PWD made, and instead maintained an air of normality in their dealing with their loved one. For example, in one case, a person with dementia felt that corrections from her family would make her less inclined to talk.

PWD 11: If they keep telling me it gets to the stage where I'm not going to talk.

PWD 7: ...they don't take any notice that I forget things.

There is no doubt that PWD in this study felt that they received ample support from their spouses although there were some issues that they felt uncomfortable discussing with them, such as the fear of being a burden. Therefore, having alternative networks in which they could discuss these issues proved important in order for them to work through the difficulties they faced due to dementia. Indeed, maintaining communication with friends and acquaintances was an important issue for the PWD. Some PWD were worried about whether other people would treat them differently when they discovered they had dementia, but for the majority of PWD were pleased to find this was not the case.

PWD 7: ...people treat me as if there's nothing wrong, you know, "Oh hello" you know "everything alright?" Different people that we know, you know...which is nice...I thought well perhaps people might think "Oh it's no good talking to her because she, you know", no people still treat me exactly the same and I think that really helps...Yes, yes, people still talk to me as if there's nothing wrong, you know, um they're, they're very nice.

This quote illustrates that this PWD felt that there was something 'wrong' with her. It also suggests that pretending things were 'normal' was a useful strategy for her, something that was reiterated across PWD in this study.

Some PWD commented on the professional support they had received from the Department of Old Age Psychiatry. For one person with dementia, his experience at the department had made him feel that he was not alone and that there were people that cared.

PWD 8: I think this is the best thing I ever did was come here. Um, with your helps and talks and all the things we've done here...er I think it's helped me think and realise that you're not on your own in this world, you know. That there is people out there that's interested, there is people out there who care. Even if you don't know them, you know like I don't know you, you know.

PWD valued the support of others and for the most part, felt secure in the unconditional support they received from their spouse. This allowed them to foster the idea of interdependence which meant that they felt that they were also contributing to their relationship. PWD also appreciated the support they received from family members and from professionals that were involved with their care due to their dementia. Maintaining a sense of normality in their dealings with their spouses, family members and professionals seemed to be

important in meaning that the support offered by these individuals was appreciated by the PWD in terms of maintaining identity and feeling included.

5.3 Summary of Chapter 5: Results for People with Mild Dementia

This chapter was split into two main sections. In broad terms, PWD discussed the *impact* of dementia on their lives and they discussed the ways in which they attempted to *cope* with it.

Analysis of their transcripts produced three key areas in which people with dementia described an *impact* of dementia: loss, relationship and identity. Most of the impacts described were negative in nature and were usually related to the decline in ability that they had experienced.

The first theme of loss saw PWD describing losses which affected their memory as well as loss of ability in social situations. In most PWD, these losses also produced a lack of confidence particularly when the world around them became less and less familiar. This often led to decreasing social circles and general activity.

The second theme of identity reflected comments made by PWD regarding their personhood. This was important since although some PWD felt they were still the same person, this mostly amounted to being 'in there somewhere' as opposed to really the same person. In fact, there seemed to be a sense of their identity slipping away. This may be due to the decline in ability they had endured coupled with knowing that the decline was likely to continue. PWD acknowledged negative changes in their temperament, the cause of which they attributed to their dementia. This may have allowed them to explain unwanted character changes as part of their disease rather than as inherently part of their identity. In turn, this could help protect PWD against the sense that their identity was slipping away.

The third theme of relationship referred to comments made by PWD about the impact of dementia on their relationship with their spouse. This theme

demonstrated how difficulties caused by dementia instigated changes within the relationship particularly with reference to role change and communication. Most commonly PWD reported changes directly associated with the disease, such as difficulty completing household chores. However, they were also aware that this declining ability meant that their spouse had to deal with the consequences and therefore endure changes themselves. Communication was a big issue for PWD, especially where they had encountered problems communicating with their spouses. Some described how they perceived a barrier between them and their spouse which hindered communication and seemed to lead to a sense of isolation. These impacts on the marital relationship lead some PWD to declare that they were a burden to their spouse. Indeed, several PWD reported doing what they could to avoid asking their spouse too many questions for they felt they had enough to do. This suggests that they felt a sense of being an inconvenience or burden.

Therefore, PWD described the impact of dementia in terms of the impact on their ability by the losses endured, the impact on their sense of identity, and the impact on their marital relationship. This represents a giant impact, for it suggests that the losses described can influence not only their relationships with their spouses, but also their own inherent sense of identity.

During the interviews, PWD were asked about how they had attempted to *cope* with their dementia. Analysis of their transcripts produced two key themes: process of acceptance, and aids to coping.

The first theme presented the process of acceptance. Being a degenerative disease means that the road to acceptance of dementia is beset with obstacles. Thus, the claim to 'acceptance' may be challenged as abilities decline and individuals regularly encounter new difficulties. PWD often told a chronological story which began with their reactions to the initial diagnosis and went on to detail how they cope with the day to day issues they faced as a result of their dementia. Throughout the process of acceptance, PWD attempted to assimilate their dementia into their person and situation by offering explanations both to its appearance and its effects. An explanation

appeared necessary for PWD to overcome the initial reactions to the diagnosis, and in particular, the question of 'why me?'. PWD furthered their journey by finding ways to cope with the day to day issues brought about by their dementia, and by fostering an awareness of what it meant to them. This understanding was key to their reaching acceptance of which the first stage appeared to be realising that nothing could be done to change the fact they had dementia. Following this, some PWD expressed contentment with their lives. PWD also described the ways in which they attempted to maintain control by altering both cognitions and behaviour, such as trying not to focus on their dementia and using mind over matter to minimise rumination. Perhaps surprisingly, PWD also found a sense of optimism to be essential to their well-being. Even though their plight was bad, they took refuge in the notion that there were people worse off than them. Some optimism was slightly misguided whereby the implications of dementia were trivialised. However, whether by default or design, this did help some PWD to maintain a level of control.

The second theme presented the aids which helped the PWD to cope and therefore, progress along the process of acceptance. Although their journey was often strewn with obstacles and difficulties, PWD were keen to try and cope with their dementia. They yearned not to let it overcome their lives and this pervaded their consciousness which encouraged them to adopt coping methods and positive thinking to help them achieve that goal. A number of mental and physical activities were undertaken that provided a sense of empowerment and optimism. Recognising their previous achievements allowed PWD to focus on the positive aspects of their lives which spurred them on to maintain a level of independence. Finally, PWD acknowledged the importance of their support network, and particularly their spouse in helping them to cope.

To conclude this chapter, PWD experienced difficulties associated with having mild dementia, but were eager to overcome these difficulties and to continue living their lives as much as was possible. Even those PWD who had endured depression along with their dementia felt that they could overcome it. PWD were aware that they had dementia but were not willing to give in to it. All PWD

were keen to do the best they could within their limits which is testament to their strong will, determination and sense of survival. They were not happy to simply survive, but wanted to survive in the best way possible.

- **Chapter 5** presented results for people with dementia. Results were discussed over two main themes of impact and coping.
- With regards to the impact of dementia, three themes were developed for people with dementia. The first theme of 'Loss' highlighted the personal losses that they endured as a result of their diagnoses such as those to their memory and ability in social situations.
- The second theme documented the way in which they felt that dementia had impacted on their 'identity' which included initial responses to the diagnosis and changes in temperament but also a sense of enduring identity.
- The third theme focused on the impact of dementia on their 'relationships' with regards to role change, communication and being a burden.
- With regards to coping with dementia, two themes were developed for people with dementia. The first theme 'acceptance' included attempts to explain their dementia, reactions to day to day issues, awareness, reaching acceptance and maintaining control.
- The second theme presented people with dementia 'aids to coping' such as mental and physical activity, recognising achievements, attempts to maintain independence and importance of support network.
- People with dementia experienced difficulties associated with having mild dementia, but were eager to overcome these difficulties and to continue living their lives in the best ways possible.

Chapter 6

Results for Carers

This chapter presents the findings for the spouses of the participants with dementia, referred to as 'carers'. See Chapter 4/Appendix 1 for a description of the sample.

As the PWD's interviews were analysed first, their themes naturally acted as a framework through which to look at the carer's interviews. The same two main issues were explored during the interviews with carers as with the participants with dementia, which were "impact" and "coping". However, the themes contained beneath these headings were somewhat different for the carers compared to the people with dementia. These differences (and indeed similarities) will be discussed in more detail in Chapter 7 which looks at couples more specifically. This chapter presents the themes for carers.

6.1. Impact

For carers, the impact of dementia was keenly felt. Perhaps this was because most of the participants were retired and therefore spent a lot of time with their spouse which meant that much of their everyday conversations and dealings were with their spouse. At the time of interview the majority of the carers had not enlisted any formal external support for their spouse (such as help with personal care), although one person with dementia did attend a day centre. As such, the carers were essentially coping with whatever problems accompanied their spouse's dementia, pretty much on their own.

All carers talked about the impact of dementia and mentioned three main areas: impact on their spouse, on themselves and on their relationship with their spouse.

The impact on their spouse included perhaps unsurprisingly, the effect of dementia on their memory, but also changes to their spouse's temperament

and confidence as a result of the difficulties associated with dementia. The impact on themselves included increased responsibility, fears and worries about their spouse and what the future held, and feeling trapped. The changes to their relationship were mainly concentrated on communicating with their spouse which presented problems due to memory, attention and personality changes.

6.1.1. Impact on spouse with dementia

The carers reported the impact of dementia on their partner to be focused on either memory associated difficulties or on changes in their spouses' disposition.

6.1.1.1. Memory associated difficulties

When the carers talked about the memory associated deficits that their spouses had experienced, they were often things that the person had done well previously. The carers were keen to talk favourably about their spouse and his/her achievements, even when essentially pointing out their deficits.

Carer 2: I mean when he was a rep he had piles of paperwork every night to see to...but now he wouldn't be able to write a letter.

Carer 7: She er, she gets, how can I put it, she sort of gets flummoxed, she gets sort of mixed up cos she cannot remember what she's she's trying, you can see that she's trying hard to, to er remember.

Carer 8: like for instance hammering a nail in, although he knows his, but he, he can't seem to hit the nail properly, he can't seem to control his hands as well as you know, they don't connect together.

There was a deep sense of understanding from the carers who, although highlighting difficulties experienced by their loved ones, were also keen to let the researcher know either that their spouse had once had a level of expertise, or that now the expertise had gone, that their spouse still made a great effort “you can see that she’s trying hard”.

The carers seemed to understand and accept that dementia meant that their spouse had difficulties with their memory and thinking. In turn this meant that although this had an impact on their spouse, their impact was generally accepted as par for the course.

6.1.1.2. Changes in their spouses’ temperament

The carers seemed less prepared for the changes they saw in their spouses’ temperament. Although these changes were no doubt also linked to their dementia, carers felt the impact of these changes more keenly than memory associated difficulties. For example, some carers spoke of how dementia had robbed them of the person they married.

Carer 6: I’m not being nasty but he is not the man I married...

Carer 10: ...in a way you’re losing the person that was when you married them if you like because this is a process that’s probably creeping up on you before you realise there’s a problem. It’s only when you look back and you realise “oh yes, that’s been happening a while” different things, and in a way it’s like losing the person you married I suppose. The changing of it.

*Carer 7: It’s another way I look at it I say ‘Well where’s my *** (wife)?*

Similarly, a diagnosis of dementia can be an emasculating experience for the husband, where the wife is required to take on a more assertive role. One

carer found herself having sole responsibility for bringing in the income when her husband was diagnosed with dementia and promptly lost both his job and driving licence. This role change was seen as creating further upset for the husband concerned.

*Carer 9: And still a trauma for us because *** (husband) was working and overnight he lost his job, and it's alright if you're retired and used to being there, but to him, you know he lost his job, they took his driving licence away from him, everything that makes him a man was taken away from him overnight... I don't think people realise what an impact it makes on a man, more than a woman, probably, because you know what men are like, he's very um, old fashioned you know, he looks after me, you know, he can't do that any longer... And, you know to him it's just soul destroying [that she has to work for the both of them], he feels guilty, and, yeah, it's awful for him.*

It could be argued that this viewpoint possibly reflects a generational view, however, the couple referred to in the quote above were the youngest in the sample, both in their early fifties. This view, especially a decline in the PWD's confidence was reported across carers whereby they felt their spouses needed more emotional support now.

*Carer 2: I'm with ** all the time now... because he doesn't like to be alone.*

*Carer 10: Whereas *** (husband) wouldn't be nervous before, he'd be quite confident, losing... he's losing confidence... he's lost a lot of confidence and that makes a difference to him.*

Sometimes a decline in confidence was linked with their spouse becoming more introvert and less likely to enjoy and engage in social activities.

Carer 2: He's more introvert now, doesn't mix well, with people he knows like you, (pause) quite happy, but with strangers, very quiet, yes, yes.

Carer 6: ...he is quieter than what he used to be cos I think he's frightened that he's gonna say things round the wrong way, and that when he's sort of talking.

Other carers noticed that their spouse had 'slowed down'. This encompassed both physical and mental slowness and tiredness that the carers linked with their loved ones becoming more dependent on them.

Carer 2: No, he seems to tire very easily yes, and he doesn't like walking like he used to, he was so energetic... and when he was a rep he walked miles in a day, but now it's difficult to get him to walk anywhere. If we just want to go to the shop there, he wants me to get the car out, yes, yes.

Carer 4: he's slowed down, he has slowed down a lot. That's what I have noticed... it does get me frustrated when he slows down cos he's always been so active, makes things, now he gets up and he just likes to sit down and then quite often about half past twelve, one o'clock, he'll fall asleep till about four o'clock. That, I get annoyed cos I don't think it's good for him.

Some carers felt their spouses had become more apathetic, with a lack of interest and motivation surrounding the things that they once enjoyed doing. The apparent preference of their spouse to just sit was described by a number of carers.

Carer 2: ...he used to enjoy doing a bit of gardening. No, no interest whatsoever now... Yeah, no motivation. They're hap, he's happiest sitting in there, watching television, yes

Carer 4: Well he seems quite happy just to sit. I suppose I should let him sit and do what he wants, it'd probably be kinder. But I think it's not good for him to sit

For another carer, it was more the idea that previous standards were now allowed to slip and that his wife seemed to have no concern that things were not being done as they would have been in the past.

Carer 5: The stairs aren't dusted down quite as often as they used to, she used to make sure she did it virtually once a day. But nowadays it's about once a week, once a fortnight depending. But er, I can live with a dusty stair.

It was hard for the carers to come to terms with changes in their partners' abilities, and those changes had knock-on effects on the everyday routine. In the example above, the carer had noticed that his wife dusted less frequently, and there was a gentle sense of resentment demonstrated in the slight hesitation as though he is convincing himself he can live with the dust. However, it does not seem to occur to him that he could help with the dusting. Perhaps he is keen for his wife to remain doing 'her' chores while she is still capable of doing so. Thus he may be reluctant to pass comment (either verbally or non-verbally) on how well she is doing for fear of knocking her confidence.

Some carers had noticed that their spouses were less able to cope with change to their routine, and this was often manifest as irritable behaviour even if their spouse had not been an irritable sort of person previously. Some carers had also noticed an increase in egocentricity within their spouse, defined by the way they wanted to talk over and over about their problems, or insisting that things be done in a way to suit them. This was difficult for some carers to learn to live with.

Carer 2: ...he's very, very placid usually, yes. So I don't know why. The least little thing used to, I mean he doesn't like his routine, doesn't like his routine altered.

Carer 8: I mean until just recently and this is probably in the last year, I think Alzheimer's has definitely taken over, (I think) I mean, he is certainly different, he was generous, if you wanted something and if you could afford it... we could have it. I think, but this past year, that's certainly you know, this, this counting his paper money, and everything to him's expensive, if it's over 50p it's expensive.

On a more positive note, one carer reported positive changes to his wife, whereby previously difficult aspects of her personality seemed to have mellowed somewhat.

Carer 7: Um, tell you, um to be honest, she's got more, I know it's, more loving, and cuddlesome...She's, she seems more placid. Do you know what I mean?

Unfortunately, such positive changes were infrequently reported by the carers. Most changes that they had noticed were construed negatively and had an impact on a day to day basis.

6.1.2. Impact on carer

This section begins by looking at the initial reactions of the carers to their partners' diagnoses. For many carers at the time of interview, the feelings that had been originally evoked by diagnosis were still close to the surface, and they were keen to tell their story and reflect on these feelings. As time wore on, the carers described experiencing further impacts as a result of their spouse having dementia. Commonly, they described an increase in responsibility as a result of having to take on aspects of everyday life that their spouse may once have done or at least taken part in. For many carers, this meant that they had

had to adopt roles that they had never engaged in before, particularly as the participants were predominantly from a generation where marital roles were clearly defined and upheld. For example, wives found themselves responsible for managing the maintenance and upkeep of their home, whilst husbands found themselves planning the meals and cooking. Carers often found that the constant decision making was mentally if not physically tiring.

The carers also worried about their partners and what the future might hold for them both and described struggling with their present situation. In addition, there was a feeling that their own lives had been curtailed by dementia because they felt they had less input into what activities they took part in and/or felt resentment that their hopes for the future or their retirement had been destroyed.

6.1.2.1. Initial reactions to diagnosis

Carers often had very emotional reactions to their spouse's diagnosis of dementia, even though they had suspected that their spouse had dementia. Despite their suspicions, carers were commonly shocked at the diagnosis.

Carer 6: I must say, well before um, he was diagnosed with it, I guessed, I thought it might've been that and I, I was trying to forget and think 'No it can't be' and it come to, wouldn't say a shock, but when it was proved that it was that, that sort of hit me

Carer 9: And even though I work with it, and it was in the back of my mind, when he was told that he had it, absolutely devastated, because you're immediately thinking it's gonna change us, us as people... you just immediately think it's gonna take what we've got, because we were so happy, and I knew it was gonna change us.

The reactions they described tended to be more dramatic than the reactions described by their spouses. This may reflect the fact that the people with dementia perhaps could not recall recent events as well as their spouse, and perhaps with time they had adjusted to their diagnosis and so the first feelings were not so fresh in their minds. Alternatively, it may reflect the sense of relief that some PWD described as finally the changes they had experienced were explained.

Carer 9: Well, for the first three months I just cried, I cried (voice cracks) every day, (starts crying) I just, everything, I just cried, and that was for the first three months, and I thought I'd never be able to stop crying.

The emotional impact of the diagnosis was still fresh for many of the carers, and often simply talking about the time of diagnosis brought all the emotions to the surface again. Carers commonly described their initial reactions to the diagnosis in quite dramatic and emotional terms. Perhaps the carers being able to recall the full experience meant that its emotional impact stayed with them for a long time.

6.1.2.2. Responsibility

Carers often felt that they had taken on responsibilities for things when they were no longer able to depend on their husband or wife to continue to do them. For some carers, this meant they felt that they had to do everything.

Interviewer: what's it [retirement] been like?

Carer 2: (pause) well for me very hard work because I have to do everything now, all the gardening, all the chores, everything now.

Carer 9: Everything, everything, and obviously you know, I, I'm not only working, trying to keep the house up together, supporting him and being happy with him, and cheerful for him,

um, and, keeping him positive, um, (pauses) sometimes I don't know whether I'm coming or going, and sometimes, that can get you down.

One carer found it difficult to manage her new-found responsibility for the upkeep of their home. Whereas her husband would have taken on the jobs himself, she had had difficulty finding alternative ways of getting things done which she did not have the necessary skills to do herself.

Carer 2: Well it does present the difficulty of finding people to do the job cos that isn't easy these days.

Some carers also reported a pressure due to having to make all of the decisions now. Whether they had made the majority of decisions previously or not, some carers found the transition to making all of the decisions had been hard.

Carer 6: it's mainly down to me to sort of make all the decisions and that...I just do it [make decisions] automatically now, I've sort of got so used to it.

Carer 11: My life has had to change slightly that way. I tend to do more now than I did before perhaps. And decisions, That's very, she won't make decisions. She says "what do you want to do?" or... and "shall we have that?" She won't decide... But that's the biggest change as far as our way of life is concerned.

Despite the inherent difficulties that the carers faced, they were often insistent that they would continue to care for their husband or wife for as long as was humanly possible for them.

Carer 6: [following a misunderstanding where they thought husband had got lost] he said 'Oh I'll have to go in a home

won't I', I said 'No' I said No, that's one thing, he'll never, as long as I can... He'll never go away.

Carer 7: So I will NOT, and I emphasise, I will NOT leave her to go to anywhere. So, I've got her 24/7.

Thus, the carers took their responsibility very seriously. The thought of not being able to look after their loved one was linked to or equated with, feelings of shame and/or failure. Indeed, the pressure of this responsibility and the need to present a normal façade was considerable:

Carer 9: we've got to keep it as normal. So it's possible that that's the way we are, that's the way we live. If it means I've got to struggle a bit more to keep it that way then so be it.

Carers had no choice but to take on further responsibilities as their partners became less able. This had practical and emotional implications for the carers as they struggled to adapt to their changing situations. However, the importance of their role as carer was taken very seriously by the carers and they endeavoured to overcome the difficulties they faced in order to continue looking after their spouse.

6.1.2.3. Worries/depressed

The carers often reported a heightened sense of worry for their spouse since their diagnosis.

Carer 1: Um, (pause) I do wake up at night and listen to see he's breathing, does worry me that.

Carer 9: I'd worry about him, or about his breathing, I used to sit and listen to his breathing all night and think...worry about him in the day.

The fears for their spouse and for their joint future seemed to manifest in a fear that their spouse would stop breathing. Although this is not a symptom of dementia, several carers spoke of listening to their partners breathing and worrying about it.

A number of carers reported struggling with their present situation whereby they felt drained, depressed, guilty or sad about it.

Carer 12: When you're tired you can't cope but you've got to cope, and the problem creates tiredness so you, you can't really win.

Carer 7: No. I do, I do um, (pause) er, I get upset with meself at times... I don't get right down or nothing, just for about an hour or so, I'll cry. But er, I couldn't get like that with her.

Carer 6: He ain't bad, I just feel sort of sad, it's a terrible thing isn't it for anybody and that.

These quotes represent a heady mix of grief, loss, sadness and tiredness for the carers to cope with. They illustrate that it is not just their own emotions that they have to deal with, but the often demanding emotions and behaviours of their spouses as well. They also were reluctant to let their spouse know that they were struggling and so tried to hide their grief and tiredness from them.

Some carers expressed feeling frustrated at times. This was either in response to the pressure they felt to present a 'coping' face in front of their spouse, or not quite knowing the best way to approach a problem and invariably feeling like they had chosen the 'wrong' option. The carers attempted continuously to do the right thing for their spouse.

Carer 9: the biggest thing that gets me down is being cheerful, and positive, because sometimes I wanna scream, and say, (shouts) I'm not positive (laughs)... I mean, the thing is in my,

my work, having to deal with people like it all day, I'm constantly being positive for people, older people all day as well, and I come home and I have to be, cheerful and positive at home, and sometimes I don't want to be.

Presenting one face but feeling very different was a hard thing for the carers to cope with. Such dissonance led to high levels of stress and feelings of being forced into an unwanted role. Indeed, although carers in the main understood that their partner was not being deliberately obtuse or annoying, this knowledge did not reduce the sense of frustration felt. Indeed, feelings of frustration were often discussed in this framework: that although the carers knew they 'shouldn't' get annoyed, angry or frustrated, sometimes they couldn't help it.

Carer 3: Sometimes I shout at him, very often I shout at him (laughs) especially if it's in the morning (laughs). No, no I do, I do sometimes argue and I think "For Christ's sake shut up woman" because it's not doing any good (laughs).

Fairly frequently, the feelings of frustration seemed to be linked to a lack of understanding about dementia and what effects it could have on a person.

Carer 2: I would have thought the penny would have dropped by now, not to do the same things all the time... But he's, he's not concentrating... and you have to say things two or three times.

This quote highlights a lack of understanding of the impact of dementia. It is unlikely that 'the penny will drop' as his inability to remember is due to his dementia rather than him not concentrating.

Most carers also expressed some concern regarding the future or worries for things that might happen. This referred to worries around how their spouse

would manage as things progressed, although mainly the carers also worried how they would cope.

Carer 6: At the moment, he's not too bad and I can cope at the moment. It's just you don't know sort of what is ahead, what sort of help we'll want.

Carer 3: I'm a bit worried about how he's going to be manage, not as well as he is now, you know. When he, when he starts wandering. I mean, he always has been a bit of a wanderer, but he usually comes back! (laughs)

Carer 8: I do think oh I wonder what, you know, how it's gonna progress, what will happen. Um, you know I, how am I gonna cope when it does, but what can you, cos you don't know really what's gonna happen do you?... It you could say right, in two years time he's gonna be so and so and so and so, or there might not be any change at all, I don't know. I suppose everybody's different are they.

Several carers had health issues of their own which they were afraid could potentially impact on their ability to care for their husband or wife.

*Carer 7: I er, this is the only thing that I'm really, really frightened of, is that I'm on eight tablets a day, angina, blocked heart. I forgets about it, I gotta concentrate on this is what I do, concentrate on what I've got to do for *** (wife)*

Carer 12: The only thing that worries me is... is how long I can keep it up. I've had two heart attacks as I told you, I had a stroke, I got Diabetes, Asthma and Angina so... and cholesterol problems.

The carers demonstrated a general awareness of the inevitable deterioration of their partners, which combined with their own health problems caused some concern about how long they would be able to manage. Some tried to focus on caring for their spouse which meant that their own health problems took second place. One carer voiced her concern that she was not sure if she would be able to continue to cope with the situation in the future.

Carer 4: You know, I shouldn't say it, but I don't think I would be able to. No, I shouldn't say that... I hope I would be able to, but I, I don't think so cos I'm not a patient person.

There was an underlying assumption amongst carers that they were expected to, and should be able to cope with their spouse. Although most carers expressed worry at how things would develop, it was uncommon for them to explicitly state that they were uncertain as to whether they would be able to continue providing such full time support as the condition progressed.

6.1.2.4. Feeling trapped

Although the carers did not explicitly begrudge their husband or wife any support, they did sometimes miss having 'me' time. The constant attempt to keep on top of things meant that they had little if any time to do the things they used to do on their own for enjoyment. They reported that their spouses hindered this further by always wanting to be involved in what they were doing. Carers therefore reported that their independence was affected by their spouses' dementia.

Carer 8: And then, I wanna go, like I'll say I'm going to the shop "Oh I might come with you" and I think Oh please don't come with me, I'd rather go on my own and do. I need, I need some time even if it's only an hour down, cos that's all I'm gone for usually.

Carer 10: I'm so busy keeping him occupied to stop him thinking about it I get quite exhausted... also I don't get a lot of what I call "me time". Because he wants to be there all the time.

Carer 9: I might just like to escape and have a bit of time for me. Well I used to... I used to sit in the bath and be on my own, just have that sort of time, relaxing time for me.

There was almost a resigned acceptance that their needs were put to one side. Even simple things like taking a relaxing bath became harder to do because of the needs of their partner. Indeed, some spouses felt that they were less able to do the things they wanted to do, because the activities they undertook were always ones that suited their husband or wife in order to keep them as happy as possible. Carers often tried to downplay the impact of having to be with their spouse 24 hours a day, for example by describing their freedom as being "curtailed a bit" (Carer 10). A decline in spontaneity was reported by some of the carer wives, which was often linked to their husbands having to give up driving.

*Carer 6: I could've said to *** (husband) "Come on let's go down there" and we could've gone down there but, yeah, yeah. I can't drive, I suppose, my fault really if I'd've learnt to drive years ago, but I never wanted to.*

However, some couples had found ways around this. For example, Carer 4 described how they used public transport and made a day of it rather than just popping into town.

Carer 4: ...perhaps catch the national coach and have a day in Bath and go to Cirencester, so it's, fortunately we've got the bus just over the road so that is no problem, we're able to get out and about. Now the summer's coming, we'll go out a bit more.

However, the lack of spontaneity and freedom was particularly difficult for some carers who had to come to terms with changes that interfered with their retirement plans.

Carer 2: (pause) Well we'd looked forward to our retirement years, going on really nice walks and trips and holidays abroad but that has all been changed now...

One carer admitted to feeling a kind of resentment at the fact that her husband had Alzheimer's Disease, although equally she recognised that he did not ask to get dementia.

Carer 8: sometimes er, I don't know whether, it's not resentment that you feel, I don't what it is really, to say you feel, you know, how you feel. I mean, you can't really feel resentful because, as I say, nobody wants to get Alz, be Alz... be diagnosed with Alzheimer's.

It was therefore difficult for the carers to know where to direct these feelings of frustration and anger. The sense of resentment was linked to the disease, but because the disease was an inherent part of their spouse, it seemed difficult for carers to separate them. This seemed to produce feelings of guilt in carers who did not wish to resent their spouses but at the same time felt unable not to.

Thus, the impact on the carer included the practical effects of their husband or wife having dementia such as the added responsibility on them, and the difficulties this caused them. It also impacted them by making them worry about their spouse and about how they might continue to care for them, which led to feelings of sadness, depression and guilt. Some carers felt trapped in their situation because they were unable to live the sort of retirement they had hoped for.

6.1.3. Impact on relationship

The impact of dementia on the relationship as seen by the carer centred around communication. Most carers reported some change in how they communicated with their spouse as a result of their spouse's dementia. These changes were brought about following their spouses' memory and functional difficulties as well as changes to their spouses' disposition. Furthermore, carers reported wanting to protect their spouse which meant that they were reluctant to discuss things with them if they thought there was a chance it would upset or anger them.

6.1.3.1. Changes to communication

Some carers reported that they found it difficult to have discussions with their spouse, saying that they didn't seem to understand them or indeed, that they had difficulty understanding their spouse.

*Carer 3: Well I can discuss things, but he doesn't really understand what I'm talking about. Um, and of course, with him being deaf, and especially if he wants to be deaf, he won't hear... you can't really have a discussion with *** (husband), he doesn't seem to understand what you're trying to get at, and if he doesn't understand, he just says, you know "Oh get on with it".*

This quote illustrates a sense of frustration whereby selective listening on the husband's part meant the carer felt it was no longer a joint relationship but rather one-sided. It also can potentially lead to confusion as to whether the PWD is choosing to understand or not. The final comment suggests that the husband was handing over responsibility to his wife in that by saying 'Oh get on with it' he was inhibiting further discussion.

A particular source of frustration highlighted by carers was that of answering the same question over and over. Some carers pointed out to their husbands

or wives that they had already asked that question, although this did not often get a favourable response and instead upset their spouses. This process is highlighted eloquently with two quotes from Carer 8.

Carer 8: I suppose I probably don't mainly do it in the right way, if I've told him something and I've told him something that's like two or three times, eventually I say "I told you that before", which probably isn't good thing to say. Then he gets a bit, you know... "Well you know there's no point you saying that to me, you know, you know". So I try not to say "I told you", I say "Don't you remember? We talked about that this morning".

This first quote highlights the dilemma of whether to let the spouse know they are repeating themselves, and if so how to do this sensitively.

Carer 8: But when you've had it, you know, I think he asked me the same question about five times within sort of an hour or so, and I couldn't understand why he hadn't taken it in. But sometimes he'll ask you a question, you give him the answer and he's not really listening. That's not got anything to do, he just doesn't listen, and he doesn't and he'll think, I'll say "We were talking about that" "Oh yeah were we, Oh I don't think I was listening". I said "Well you've got Alzheimer's, do you think you could try and listen?" (laughs).

This second quote suggests that the carer believed her husband occasionally engaged in selective listening and she demonstrated how she dealt with this in a humorous way. This quote highlights that the carer perceived that not all their communication problems arose as a consequence of dementia. Again, this outlines the difficulty couples suffer with regards to being able to disentangle whether problems are attributable to dementia or other factors.

Changes in their spouses' temperament also affected communication between couples. Some carers felt that their partners displayed a lack concern for others. Carers found this was difficult to adjust to and was particularly potent for the two wives below who felt their husbands were unconcerned if they were upset or ill.

Carer 2: I don't think, he hasn't got that concern that he used to have, you see...if something goes wrong, it just doesn't seem to register, do you know what I mean?

Carer 8: this sounds wicked, he sometimes makes you feel that he's the only one that has anything wrong with him. That although I have things wrong with me, mine are not obviously as important as his. That sounds like a silly child, but that's how we feel.

This feeling that their needs were not being addressed or even heard, added to the sense that their relationship had become one-sided. This was difficult for carers to deal with because they felt that their spouse did not care, but equally carers felt uncomfortable 'criticising' their spouse because they were aware of the impact of dementia on their spouse. One carer acknowledged that how she dealt with her husband's questions depended a great deal on how she was feeling herself.

Carer 10: In fact, how you deal with it is a lot of how you're feeling yourself that day. I think you know it really does depend on that as well... And just occasionally if you're not feeling that good yourself... you shouldn't do but you say "I've already told you half a dozen times" you know, but... you know, but we talk to each other about that. And I say to him "I'm sorry if I do do that occasionally, but I'm only human too". Yeah, but we'll talk about it.

This quote illustrates that there was often a difference between how carers felt they 'should' act and how they 'wanted' to act towards their spouse. Trying to act as they felt they should do led to feelings of remorse and regret when inevitably the carers were unable to keep this up.

6.1.3.2. Protect spouse

Carers were eager to protect their spouse from becoming upset. Some achieved this through communicating sensitively with their partner, and by talking through difficulties. However, many found that the ability to discuss things with their spouses was hampered due to the fear that they would take it the wrong way and get upset and/or angry. This led some carers to change the way they communicated with their spouse in order to avoid any upset or confrontation.

Carer 8: but the trouble is now as well, although he was quick tempered before, now I have to be so careful I think, if I, what I say that he just takes umbrage at it and then he won't speak for two or three days... Yeah, he'll talk to the dog and the cat but he completely ignores me (laughs) for a couple of days and then I'm thinking what did I say? I have to think what did I say? and I think well I'm sure I haven't said anything that bad... But maybe to him I've said or done something that's annoyed him, which I obviously have done. And I'm sure that I do lots of things that annoy him.

This difficulty in reading cues from their partners often led to communication problems. As the quote below shows, this sometimes led to a change in the carer's behaviour whereby they would let things go that previously they would have discussed.

Carer 7: As I say, I don't get, I never get uppy with her, I just, I just say "Well if you think so", that's it (chuckles)

In addition, a number of carers felt reluctant to burden their spouses with their worries, whereas they would have discussed them previously.

Carer 2: I wouldn't burden him with something that was a worry to me, no I wouldn't do that, no

Interviewer: Do you ever talk to him about that [worries about the future]?

Carer 3: (very quietly) No

Interviewer: Why?

Carer 3: Well I just don't want to upset him, plus the fact that I don't, I don't know that he knows exactly what's gonna happen, although, I mean, he sees my Mum [who has AD], he doesn't go down [to see her] as often as me.

The dementia also caused some carers to reflect on their own habitual behaviours. For example, one carer recognised that during their lives she had been the one to argue or to hold a grudge but she realised that she might have to change her ways because she felt it was unfair to upset her husband unnecessarily.

*Carer 4 Yeah, he's um, I am trying to let a lot lie, ignore things, but for his sake not for mine. For ***'s (husband's) sake.*

The 'trying' in this quote highlights that this carer was making a huge effort to change the behaviour of a lifetime for her husband's sake. It was not something that came easily to her, but she was encouraged by his positive response which helped her to continue trying.

The carers wanted to protect their spouses from any more upset than was necessary with having dementia. They did this by changing their communication patterns and being careful how and what they discussed with their partners. This, however, sometimes meant that they had no-one to discuss their worries with. Whereas their spouse was once primary confidant,

now it seemed that this part of the marital relationship had diminished. For those carers who did not have other people to turn to, it was very difficult to come to terms with, and sometimes led to a sense of frustration and resentment.

6.2. Coping

The presentation of the impact dementia had on the carers showed that although there were common themes running through the carers' experience of having a husband or wife with mild dementia, there were differences in how the carers felt about these experiences. This is not a surprise as all people perceive, experience and deal with things differently. However, it is important to try and capture what did work for the carers and if possible to try and ascertain why it helped.

The second half of this chapter will focus on the coping efforts made by carers. This fell into three areas that detail the coping strategies used, how carers tried to maintain feelings of couplehood, and external support.

6.2.1. Coping strategies

Having a spouse with mild dementia inevitably means there will be difficulties to contend with. As we saw in the impact section, the carers recognised a decline in their spouses' memory and functionality, as well as changes to their spouses' temperament. Carers had to find ways to deal with these changes in addition to dealing with their own feelings towards the changes in their loved one. The coping strategies adopted by carers can be described in two areas: those where cognitions were altered in order to foster a positive outlook and those where behaviours were altered. Both of these strategies enabled the carers to restore a sense of normality which appeared to represent successful coping in their eyes.

6.2.1.1. Development of positive cognitions

This refers to the way in which the carers thought about their husband or wife having dementia. Within this, carers talked about information-seeking, limiting rumination on the subject, thinking positively and generally developing the sense that things could be worse. As such, carers highlighted that they were keen to make the best of their situation. Finally, a number of carers felt confident in their ability to care for their husband or wife. This confidence had developed as they had come to terms with the fact their spouse had dementia, and had developed ways of coping that were successful.

Some carers recalled wanting to know what the future held when they were first told that their husband's had dementia. They described the importance of seeking information about what to expect and the anticipation that this would enable them to better cope with the future. The explanation that everyone is different and therefore no clear picture of what to expect can be given, was met with disappointment. However, Carer 9 felt that having some information was better than none.

Carer 9: I think from the time you hear it, you know, and you need help for the first six months... You also need somebody to come out and talk to you, about Alzheimer's, what its like, the first stages um, because automatically you think, cor this must be awful, and it's not necessarily.

As we saw in the 'impact on carer' section, carers often described the time around their spouse's diagnosis to be emotionally very difficult. Accounts of crying, depression and despair were not uncommon. Juxtaposed with an initial yearning for information, carers also appeared to reach a point where they wanted to limit the amount of ruminating they did regarding their husband or wife's dementia. The following quote shows how the carers were reluctant to dwell on the fact that their spouse had dementia, often as much for their spouse's sake as for their own. Again, this demonstrates their devotion to their loved ones.

*Carer 2: But you can't go back can you, what's the point...
There's no point in it... He, he brings it up sometimes and I try
to brush it over because you know the past has gone and that
was a different age.*

As such, carers reported taking each day as it comes, which seemed to be another form of not dwelling on what might happen in the future. In this philosophy, carers tried to deal with things as they occurred rather than ruminating about what might occur.

*Carer 6: we just take day to day really. That's all you sort of
can do.*

*Carer 8: So, but I've, my daughter says "What you gonna do
Mum?" I said "Well you just have to cross that bridge when you
come to it", don't you, what can you do? You can't start, you
know, what can you? You can't do anything now... I mean if
you could do something and think "Oh well that would sort that
out for the future" you could do it. But I don't really see that you
can do anything.*

*Carer 4: I think you have to deal with things as they crop up.
Not wait till they get worse and then it's harder to deal with I
think.*

The future for the couples was unknown as they had no firm idea of how or when it would get worse, which meant that it was difficult for them to prepare for. Accepting this seemed to make it easier for the carers to live in the present.

Carers also began to consider the wider picture and appreciate that despite their problems, there were many people worse off than them.

Carer 4: Not in no way would I say I'm hard done by... It's just a little bit of pressure which could be a hell of a lot worse, couldn't it?

Interviewer: Ok so the feeling of why does it have to happen to us, is that still there or is that...?

Carer 9: No it's gone. Why shouldn't it happen to us I think now. It's better than it happens to somebody else that probably couldn't cope with it. And we both think now... well you know we're getting older now, chances are you're going to get something anyway so we're both learning to accept that and if it hadn't have been this it would have been something else, something worse even.

These quotes illustrate how the carers attempted to rationalise their situation through downward comparisons, counting their blessings and focussing on the fact that they could cope better than others. Keeping in mind that their situation could be much worse seemed to help the carers by enabling them to focus on the good things and be thankful for what they did have. Most people take for granted that their spouse knows who they are, but the carers were thankful for these small mercies which had the ability to brighten their day.

*Carer 1: And it's lovely when you wake up in the morning and he says "Hello ***". Thank God, you know, he knows me... it's hopeful when, you know, at least he doesn't wake up and say "Who are you?". Yeah (laughs)*

Carers also tried to minimise the impact of specific difficulties or dementia in general. This was evident in some of the carers' interviews as far as how they chose to describe the difficulties they faced.

Carer 1: He has a little attack of the Alzheimer's you know his, um he can be like really away with the fairies.

This type of response was fairly typical as a means of downplaying the condition. Rather than dementia being considered a chronic long term condition, carers described it as a 'little attack' or similar. This seemed to help lessen the seriousness of the situation they described.

The following quotes illustrate how this carer felt happy with their current situation despite its difficulties, given that they knew it would only get worse.

Carer 4: It's not a bad situation that we're in, um I think we're both reasonably happy as it is because we know it is gonna get far, far worse.

Carer 4: I suppose I should be thankful cos as I say it's gonna get far worse.

The knowledge that it was likely to get worse seemed to provide more motivation for counting blessings and for living in, and making the most of now. Developing a positive attitude was heralded by several carers as imperative to coping well with a spouse with dementia. Often they commented that a positive attitude rubbed off on their husband or wife which helped all round to make the situation easier.

*Carer 1: Well I, I think it's if your attitude is positive... and I think your attitude has got to be positive or else it won't be positive with ***, it won't be positive, it won't rub off on him, and he's positive that he's gonna get over it rubs off on me...*

Carers described a number of ways in which they thought about the fact their husband or wife had dementia. Following the initial shock of diagnosis, these thoughts were generally positive and aimed at providing some perspective and normality against the changes that had occurred with the disease.

6.2.1.2. Altering behaviours

In order to restore a sense of normality in their lives, carers also described changes to their behaviours which they felt helped to develop an air of familiarity. Certainly the sense that they felt they had to take on the role of 'boss' was evident among the transcripts. In this role, carers were on hand to provide their husbands or wives with motivation and encouragement meaning that they were generally busy, as well as ensuring that orientating routines were stuck to.

Most carers said that they felt responsible for ensuring that their husband or wife maintained an active role in their day to day lives. In most cases this was upheld by the carer suggesting that their loved one get involved, and in some cases the carers continued to do this despite the jobs not being done as well as they used to be. It was strongly felt among carers that their husbands and wives should be encouraged to take part and continue to do things for as long as they were capable. This was to ensure that skills were not simply lost through not using them, and also to help make their spouse feel that their input was needed and valued.

For example, some carers recalled ways that they had tried to help their partner by asking a series of questions to enable them to work it out on their own, rather than telling them the answer immediately.

Carer 5: I try, if she asks me something about, you know sort of like she's asked me for about two or three minutes before, I try and ask her a question back so that she can er, give me the answer without me having to tell her again.

Carer 10: Yeah because a lot of it I tend to like... for instance he'll forget where a key belongs or which door... drawers, like say he's drying up and he's putting things away...but if he says to me... he'll stand there with something and say "Where does this go?" I try and give him clues to try and work it out himself.

For most carers, doing things together with their partner enabled them to reinforce the idea that their contributions were needed and valued.

Carer 7: ...cos what we've started doing is going to the Co-op, buying some sandwiches and making like a picnic, right there on the seat, we take er some, and a couple of bananas and some sandwiches and she's, she's happy and she knows the people, cos we get to know so many people, while we're sitting there, cos so many people walk past with their dogs and they stop and they chat and they talk away to her and they talk to me, so we've um, we've got quite a, worked up quite a friendship between these people... Yes, it is quite good. I think it keeps her mind working.

This quote shows the importance of developing a routine in which the spouse with dementia continued to play a central, albeit superficial, role. This served to normalise the situation, and in this last case 'normality' was further reinforced by the involvement of strangers in the routine. They provided a sense of normality because they were unaware that the wife had dementia and therefore did not alter their behaviour towards her. This seemed to enable the carer to forget about her dementia at least for a while.

The development of routines which allowed the person with dementia to maintain a level of independence also seemed a popular way for carers to provide their husband or wife with feelings of security. More regimented routines arguably helped to orientate their spouses and by doing repetitive tasks meant that spouses could continue to be involved despite their memory and functional deficits. All of the carers interviewed had some degree of routine that they upheld with their partners. Routine referred to any activity done on a regular basis such as making lists for the food shopping, having a rota for the washing or taking part in activities such as day centres or physical exercise.

Carer 7: we keep to that routine... She turn round and say that's it, bedding day today or like, smalls, different things

Carer 11: we do lists. Shopping lists. We were doing it just before you came in actual fact. We work out the meals for the week and then a shopping list you see and that kind of thing. She makes little notes on her calendar in particular you know.

The carers generally did very well at including their partners in activities and keeping them involved in day to day chores. However, as we saw in the impact section, many carers yearned for some time on their own to pursue their own interests or even to just have a relaxing bath! The following quotes illustrate how the few carers who did manage some 'me' time found it very beneficial.

*Carer 2: Well if I get, if I get a bit down, and things get a bit on top of me and *** (husband)'s at (day centre) or thing, I just go down for a walk. And I invariably bump into somebody and have a little chat, so that helps me, yes, yeah... and it helps you forget, you come back and you feel fresher, yes*

Interviewer: Do you think that's helpful for you to have the time?

Carer 6: Yeah, yeah cos it do, although as I say we get on alright, it's just nice for me just to have a little, do what I wanna do without thinking "Oh well".

Therefore, it seemed that doing something on their own brought with it a sense of normality and ability to recapture their sense of self. However, as we also saw in the impact section, often the partners with dementia were keen to accompany their carer everywhere. Coupled with an eagerness to keep their spouse happy, perhaps carving out 'me' time quickly falls down a carer's list of priorities.

In order to successfully develop behavioural strategies for coping with dementia, it appeared necessary for the carers to begin by altering their thoughts about their spouse having dementia, because a sense of acceptance allowed them to devise ways to recapture a sense of normality within their lives. The acceptance of what dementia meant for their spouse at that time allowed carers to take on the role of boss and to encourage their spouse with minimal feelings of resentment and frustration, all because they understood that their actions could have a positive impact on their spouse.

6.2.1.3. Restoring normality

Carers seemed to aspire to reaching a sense of restored normality within their environment. Following the emotional upheaval of the diagnosis, carers attempted to alter cognitions and behaviours motivated by the desire to recapture a sense of normality.

Several carers had reached a stage where they felt confident that they could cope with the present demands associated with their husband or wife having mild dementia. There was often a sense that following the initial shock and emotional reaction to the diagnosis, the actual lived experience (at least at this stage) was not as bad as they had first imagined it would be. For several carers, this meant they were able to recapture some normality in their lives, which they had first thought they had lost forever. As we have seen, coping with new challenges associated with dementia was tricky for the carers, particularly where the changes affected the person who they felt their husband or wife was. However, a number of carers also reported that they had since devised ways to cope with these problems. This was made easier particularly as the changes came to represent the norm, and carers accepted their occurrence as commonplace, at least for them.

Carer 6: if he happened to say, forget what I said or something, we'd just laugh it off...and that cos I, not being funny, cos I'm getting older, I can go out finish with and I want someink and I'll get where I'm going and I've forgot what I

want, but it do, like remember it in the end. I mean and then I laugh and I say well I've caught it off of you and that... and we just sort of laugh it off and, that's all you sort of can do really.

This quote illustrates how the carers tried to use humour to normalise the situation. Furthermore, they endeavoured to maintain a sense of normality around their spouse by encouraging them to remain involved in day to day activities. The sense of having good and bad days appeared to help the carers to remain positive whereby 'normality' seemed more achievable if they saw glimpses of it.

Carer 10: Well you carry on as normal. Ok we have some abnormal days but we mostly carry on as normal.

Carer 11: Well they're [things are] not normal no. As we... before this... no no as before she developed this problem, no. No. Not as normal as they were then, but as normal as can be yes. It hasn't disrupted our life at all really...

Carer 12: right from the start I tried to treat her as normal and encourage her to be normal in everything she does... as much as you can. And I think it's worked. If there's anything she wants to do then I allow her to do it. She actually cooked me roast dinner for the first time last night in about two months. All of a sudden she says "I'll do that", I thought oh God here goes the meat you know because it usually comes out like a biscuit but... but no it was quite good. So in other words she has got good days.

A strive towards normality or at least ensuring dementia had a minimal impact on their lives was present across the carers' interviews. Normality was restored or at least attempted, by changing both cognitions and behaviours as a result of changes due to dementia.

6.2.2. Maintaining feelings of couplehood

The second aspect of coping refers to carers describing how they coped with the impact of dementia on them and their spouses as a couple. The carers in this sample all considered their spouses to be their husband or wife, first and foremost. They were, without exception, keen to illustrate that their husband or wife essentially remained somewhere beneath the outward changes to their abilities and temperament. Feelings of couplehood were maintained by the carers in two ways: first were existing ways that had endured despite dementia, and secondly were new methods that carers had developed in response to dementia.

6.2.2.1. Existing methods of couplehood

All of the couples reported having at least 'good' marriages and being pleased with what they had achieved in their lives. This meant that feelings of love, respect and fulfilment in their relationship had endured. Carers reported still needing their spouse to maintain their role as husband or wife, as well as accepting that they now had caring duties towards them. Carers remembered how they had felt about their spouse when they were younger and enjoyed reminiscing about the good times they had enjoyed with them.

Carer 3: ...we were very happy together. Well, we still are really... We're just not swinging our arms over each other and rushing up the bedroom like we did. (laughs). But then again, he's 80 and I'm nearly 70 (laughs). But er, no, we've had a reasonably happy marriage.

Carer 9: Yeah, um, we, we've travelled a lot together, and very, very close and we've seen a lot together, um, so we've had a wonderful time, together, uh, and you can't replace any of that.

The joint positive experiences described by carers seemed to count the most towards them feeling fulfilled and happy in their marriages. Coming up to the present day, several of the carers reported feeling romantic towards their spouse and were happy to be married to them.

Carer 1: ...we go to bed, er when we go to bed we go to sleep holding hands. Stupid isn't it, 85 and 72! (laughs)

Some carers felt that their husband or wife had changed due to dementia but they were also adamant that they were still their husband or wife and would remain so. Dementia had not stolen their spouse from them.

Carer 6: I still, as regards, I still loves him and he's really is the same, person, I suppose but he isn't cos he's, he used to be, um what could I say, quite talkative and, and that, but now you sort of, his forget, his memory's gone, he's sort of, I think he gets a bit, well not shy of talking because he thinks he's gonna get it sort of muddled.

*Carer 12: ***'s (Wife's) in there if you could put it that way.*

These quotes suggest that the carers saw that elements of their spouse still existed, although they did so in parallel with dementia. It seemed that they sometimes had to look hard to find them, for example 'Wife's in there...' However, despite this, the carers often spoke of how lucky they were to have their partners, and that they still needed them as much as ever.

Carer 1: I just can't imagine ever being without him, you know, he's such a nice man, he is. I'm very fortunate.

The carers were asked about whether they saw caring for their spouse as part of their remit as their husband or wife. The majority of carers expressed a desire to care for their husband or wife, whilst a few felt more obliged to care for their spouse because they were married.

Carer 5: I married her for better or for worse, love. Unfortunately the worst has come out, somewhere... I'm not, I'm not, not happy. I think happy would be the wrong word, I'm prepared to do it and happy to do it, but I'm not happy about it... I love her. I really do. She's been a very good wife to me and a bloomin good Mum to my boys. (pause) And we've known each other for over 50 years now.

Carer 3: When I got married, I got married for life... For better, for worse, richer, poorer... we don't do as much together now as we used to, but I mean, he's still my husband, he's still the father of my children. (pause) and he's still a damn sight better than a lot of people, so.

Some spouses were aware that their feelings towards caring for their spouse, or indeed their ability to continue caring for their spouse might change as the dementia progressed.

Carer 3: Well in a few years time, I don't know, my answer might be different, but well you don't know what's gonna happen in the future, (pause, and then quietly) and well maybe it won't be too bad.

Carer 8: Um, I suppose I'm willing really to do it, yeah. I am expecting it, I mean I don't really know what to expect, but all I can see, everything you see and read, you think "Well it's got to get harder" I would imagine, unless they suddenly get some miraculous breakthrough with, with something.

Whether caring was part of the marital role seemed to reflect how happy the marriage had been. Those carers who had had more tempestuous experiences of marriage seemed to feel more obliged than those carers who had had comparatively easy happy relationships.

6.2.2.2. New ways of maintaining couplehood

The presence of dementia meant that some carers had to adapt and find new ways to keep their relationship one of 'husband and wife' rather than allowing it to become one of 'patient and carer'. For some carers, this was done by fostering a sense of togetherness through spending a significant amount of time with their spouse. This did not suit all of the couples, but for those who had always done things together, it was helpful for the carer to be able to maintain this. Carers also tried to protect their husband or wife, usually in social situations, from making mistakes due to their dementia, such as repeating themselves in conversation. In general, carers often tried to help their spouse to maintain their identity or who they were.

All but one of the couples had retired which meant that most of the carers found themselves spending much of their time with their husband or wife. As we saw on the 'impact on carer' section, some carers found this difficult to manage due to the impact it had on their own time.

Carer 8: since my husband had to stop working abroad, we virtually spent all our time together, which, came a bit hard to me, I have to say... I wasn't used to having to worry about what somebody else was doing. (chuckles)

However, for a number of carers, spending increased time with their husband or wife helped to enhance feelings of togetherness.

*Carer 2: More together since ***'s [husband's] had his illness, but before we did do a few things separately, but we enjoy each others company and our interests are almost the same so we enjoy doing things together... I'm with *** all the time now, apart from on the days he goes to day centre.*

Carer 9: we still have something special, which is good. It makes you enjoy every moment... we cherish every single moment, every single day... In actual fact it's brought us closer together because you know every day's a bonus for us. You know it's lovely, you cherish everyday now, you really do. Just cherish every day... It's made us closer and I didn't think that would have been possible but it definitely has.

The differences in wanting to spend time with their spouses (or not as the case may be), probably reflects their relationship historically and also affects the suitable coping strategies for each person. Spending every moment with ones spouse may suit some individuals and couples but it does not work for everyone. There are no failsafe rules about coping with dementia, except to be duly supported to enable individuals, couples and families to try and discover what works for them.

Some of the carers in this sample tried to protect their spouse from making mistakes or feeling left out in social situations. This may have helped enhance feelings of security for the person with dementia, particularly if they were worried about people noticing their mistakes. Furthermore, it would arguably enhance feelings of togetherness and couplehood if together they developed ways to cope with social situations which allowed socialising to be a pleasure rather than a chore.

Carer 11: I protect her in a way I suppose from other people noticing, you know what I mean?... We sing in the church choir, and sometimes she'll forget what hymn it is or which book to pick up, you know that kind of... so I nudge her and point it out, yeah. It's silly little things like that really.

Generally, carers were keen to help their spouse maintain their identity, either through being supportive in social situations as we saw above, or by maintaining roles and responsibilities as appropriate. Carers were often keen

that whilst their spouse had the ability to do something that they should continue to do so.

Carer 3: ...he still goes in and pays the bills, and I sometimes think should I put that on DD, direct debit, um but then I think well no because you're taking everything away...I like to give him that little bit of responsibility.

Carer 10: I make sure he still feels useful. I say to him "oh can you help me do that because I can't do it" so "yes of course of I will", so he goes out. The only other things he'll do without being prompted is the topping up all the feeders we've got in the garden for the pets, the wildlife.

The last quote illustrates an underlying assumption that PWD are not inherently useful, hence the carer taking on the responsibility to ensure that her husband feels useful. This may reflect stereotypical beliefs and/or the impact of dementia on her husband if it has meant he was not able to continue to be 'useful' in the ways he did previously. Maintaining feelings of couplehood in some way was important for all of the carers. None of them had given up on their marriage because their husband or wife had dementia, and in fact, most carers found themselves more dedicated to their spouse.

6.2.3. External support

The importance of external support, or indeed the lack of it, was evident throughout carers' interviews. It became clear that with sufficient support from others, carers' ability to cope was largely improved. Carers gave examples of positive and negative experiences regarding external parties, most commonly family, friends and neighbours.

6.2.3.1. Positive aspects of external support

Most carers did not yet require day to day input to help them to care for their husband or wife, mainly because the sample had 'mild' dementia and they were managing relatively well with any difficulties. However, carers did talk at length about the emotional support they received from family and friends. Some family members helped out with practical things such as driving, which the carers were thankful for.

Carer 6: She (daughter) takes me and if I wanna go anywhere or we wanna go anywhere, she takes us. It's not a chore, she, she do go out in it and that.

In the main though, family members (mostly adult children) supported their parents by being there for them, and by being interested in their lives and keeping them involved in what they were doing.

Carer 9: They're good. Absolutely, they're all wonderful, um, they can't support us financially or physically, really, but, they're all, mentally very supportive. I think it's brought them all closer together, and, because they've all got his interest at heart.

One carer noticed how her husband's children had rallied around since they discovered the extent of their father's difficulties and how much it was distressing him.

Carer 10: When people don't see you all the time they don't realise how much of a problem it can become, and since his eldest daughter, breaking down in front of her, she has told her youngest sister, now all of a sudden she's ringing up "if you want to go for a walk Dad I'll go walking with you". It's a bit more input now than there was. I mean they're always there if you want them but you'd have to ask.

This quote illustrates how the carers often had to actively reach out for support. For many this proved difficult as they didn't want their family members to worry, especially when they perceived their relations to have enough worries of their own.

Some carers talked about their neighbours and the supporting role they played. For some carers the neighbours acted as confidant and for others, the neighbours were there to keep an eye out for their husband or wife while they could not be there.

Carer 9: They're [the neighbours] very good, you know if ever I needed somebody they're there which is great and that's a big plus. A big plus for me especially being at work.

*Carer 10: But all the neighbours without exception have said if ever we need any help don't hesitate to ask. They've been very good. Yeah. And they all know what's wrong with *** (husband).*

Several carers discussed their friends and support they provided. The carers seemed to be pleased when they could attend social gatherings at which other people did not notice that their husband or wife had dementia. Similarly, carers seemed pleased when friends commented that they had not noticed any change in their spouse. This seems to suggest that their partner's behaviour had the potential to embarrass them.

Carer 7: yesterday we went round the club and she was different altogether, chatting away to, nobody really knows that she's, round there like, that she's got Alzheimer's. Well a couple of fellas that I really know, they know but er loads of them don't know, she just goes, she speaks to them and she knows those

Carer 11: I mean our friends know that's she's suffering this early cognitive memory thing, but they say they don't notice it. I do, I notice it. But they say they don't, I don't know whether they're being kind or not, I don't know.

The above quote illustrates how the carer suspected that his friends were being kind by saying that they had not noticed a change in his wife. He seemed to suggest that although being kind is well-intentioned, it nonetheless rendered him unable to discuss his situation in real terms. Instead he may have been forced to project a sense of normality which to him seemed insincere since he felt it was obvious to all involved that 'normality' was not the case. On the other hand, one carer found that people were more understanding once he had told them that his wife had Alzheimer's Disease. They had previously thought she was snubbing them.

*Carer 7: Oh they're very good, you know they, they now say "Hiya *** (wife)" now they don't think that she's er gets stuck up. [Friend], she said, "****'s (wife's) got stuck up, she don't speak". And I said to her, "well I said I'm telling you now that ****'s (wife's) got Alzheimer's. I said she wouldn't recognise you". And that... went and told her "Oh" she said "Oh I'm so glad now that you've told us". And we tell, I tell everybody now.*

The initial response from some carers was to hide the diagnosis and only reveal it under duress. However, the experience of positive and supportive reactions from family and friends often empowered the carers to disclose it to others. One carer who was still working, found that her colleagues were a great support for her.

Carer 9: But the girls at work are very good though because they understand me. And that's where I do all my talking I suppose.

It seemed important for the carers to have an outlet: one person or a group of people that they could talk to. This opportunity to talk unhindered about their situation enabled them to work through issues and gain feelings of support and strength.

6.2.3.2. Negative aspects of external support

Some carers also had difficulty accessing external support from their families and friends either because they were reluctant to discuss issues with them, or in some cases, admit to others that their spouse had dementia at all. The reluctance to talk to people about their worries or problems was mainly because the carers did not want to burden their family and friends with extra worry. Some carers also found it difficult to talk openly to people about something they considered to be quite private.

*Carer 8: ...can talk to [daughter] but she has a job to understand it because, I think being from a, next generation being younger, she's never been where, like for instance she'll say to me "Oh do you wanna go out tomorrow Mum, I'm going to wherever, Ikea or something" I say "Oh no, I don't think I can come, I don't want to leave your Father all day on his own, I'll have to see what he says" and *** (daughter) said "I can't understand why you have to ask him".*

One carer had unfortunately had a bad experience with friends whereby her husband's friends had stopped calling by since they found out he had dementia.

*Carer 2: we don't get so many friends coming to see us, since they've learnt that *** [husband] has dementia... It is a shame. We always had people popping in. I don't know whether they don't know exactly what dementia is and they feel embarrassed, but that's er, that has upset me a bit.*

The negative aspects of external support centred around the carer having to deal with demands and lack of understanding shown by family and friends. As a result, some carers felt reluctant to burden their families and friends by discussing problems with them. Some carers had tried to discuss things but were put off by unsatisfactory responses from their families. There was a sense from one carer that her family tried to placate her rather than actually listening to her.

Summary of Chapter 6: Results for Carers

This chapter was split into two sections which addressed the *impact* of dementia and how carers *coped* with it.

With regards to *impact*, evidence was presented which details carers' understanding of the impact of dementia on their partner with the disease, the impact on themselves, and the impact on their relationship.

The carers were very aware of what effects dementia had had on their husband or wife, and were able to talk about the difficulties they faced as a result of these problems. This was often a fairly descriptive phase of the interviews where the carer described the memory and functional problems they had noticed in their spouses. Many carers also noticed a decline in confidence, and increase in apathy and irritability which they found much more difficult to cope with. This seemed to be mainly because the presence of these factors meant that their spouse seemed less like the person they had married. For example, carers described the fairly benign notion that their spouse forgot where they put something, compared to more emotive observations such as their spouse not taking part socially due to a lack of confidence or their spouse becoming irritable and agitated if their routine was changed even slightly.

This leads onto the impact on the carers themselves. When they were initially told that their husband or wife had dementia, carers often described a sense of shock at the diagnosis. This was despite the fact that most carers suspected that their husband or wife did have dementia. As they adjusted to the news,

carers worried about their spouse and a felt a number of difficult and often contradictory feelings e.g. depression, guilt and sadness. Several of the carers felt they had added responsibility since their husband or wife was less able to do things. This was often to the extent that they felt they made all of the decisions, even down to what they would eat each evening. The majority of the sample had lived fairly traditional lives whereby the roles of husband and wife were neatly segregated and understood. Therefore, having to suddenly undertake new roles and be fully responsible for their outcome was found to be stressful for carers. Although each carer was dedicated to their husband or wife, some did also admit to missing the 'me' time they used to have, or expected to have during retirement years. Furthermore, some carers felt trapped because their freedom had been curtailed due to their spouses' dementia.

Thirdly, carers described the impact of dementia on their relationship with their husband or wife. Most pertinently, carers noticed that their spouse having dementia had meant that changes had occurred regarding the ways they communicated with them. In some respects this was due to the memory or functional difficulties that their spouse had, for example, asking the same question over and over. Some carers admitted to finding this difficult to cope with. Communication had also changed due to perceived changes in their spouses' dispositions. For example, carers perceived their spouses to be more sensitive or irritable than previously or to display a lack of concern for others.

As outlined throughout the first half of this chapter, the 'impacts' felt by carers all differ in their levels of severity, intensity, frequency and distress. There is no doubt that all of the carers had experienced some level of impact as a result of their husband or wife having dementia. What is also clear is that although each change had impacted on their lives, some of these changes were easier to cope with than others. Indeed, it seemed that it was not the memory problems per se that were difficult to cope with, but rather the further implications they had such as difficulties communicating with their spouse, and a lack of independence. This also differed between carers whereby the severity, intensity and frequency might have been the same, but the distress

experienced by different carers with different outlooks, expectations, and coping mechanisms could be very different. Therefore, the degree to which carers felt dementia had affected their lives depended on the specific impacts they had experienced, as well as how the individual carers attempted to cope with them.

With regards to *coping*, the three themes for carers were coping strategies, maintaining feelings of couplehood and external support. These themes represent the important aspects of coping for the carers all of which illustrate how their ability to cope is regulated by a variety of influences.

In the coping strategies theme, the strategies adopted by the carers seemed in general to foster a sense of restoring normality, particularly following the emotional diagnosis period. On the whole, carers seemed to restore this sense of normality through altering their cognitions and their behaviours. There seemed to be a process through which they developed a positive outlook which began with seeking information following the diagnosis. This was followed by a desire to limit the amount of rumination about what could happen as this was felt to be counterproductive. At this point, carers developed positive thought processes that helped them to come to terms with their partners' dementia. For example, carers were pleased when they and/or their spouse were able to resume activities or return to day to day living after the shock of diagnosis. The fact that they were able to achieve this was felt to be an achievement in itself not least because it meant that they were able to maintain their relationship with their husband/wife despite dementia. As time went on, carers also developed a sense of perspective, that although their situation was not ideal, there were plenty of people who were worse off. Some carers even said that they felt lucky: at least they still had their spouse. In terms of altering behaviours, some spouses introduced routines to help keep their spouse orientated and to maintain their independence as much as possible. Other things included doing activities that their spouse enjoyed and encouraging their spouse to keep active.

There were two further aspects of coping that were seen across the interviews, and which figured prominently in the carers' lives. The first makes up the second theme of maintaining couplehood in which carers described both the existing and new ways in which they attempted to maintain a sense of togetherness and couplehood. This meant that carers kept alive the notion of being husband and wife rather than allowing the relationship to transform into carer and cared for. Most of the carers were happy to care for their partners, particularly if they had had fun, enjoyable lives together. However, a minority of the carers who had experienced more difficult marriages felt of a sense of obligation to care for their spouse. Regardless of this though, all carers were keen to do their best for their spouse and as such strived to cope successfully with the challenges that faced them.

The final theme under coping was external support. During analysis it became clear that external support, be it positive or negative, had a big impact on the coping ability of the carers. Carers that had good emotional external support really felt they benefited from it and it enhanced their coping ability not least by being a further weapon in their own coping arsenal. Conversely, those carers who had had negative experiences with friends and family often found it quite upsetting. Having to navigate others' lack of understanding and insensitivity was difficult for the carers to cope with in addition to everything else. There was also a sense among some of these carers, that their family and friends should have been more supportive without having to be explicitly directed. However, some carers who did persevere with family and friends were pleased with the eventual outcomes. It seemed that good external support in which family and friends worked hard to include the person with dementia, further fostered a sense of normality for the carers.

For carers, the overall aim of coping seemed to be to restore and/or maintain a sense of normality for them and their spouse. There were a number of ways in which they attempted to do this as outlined above. It seemed that having a sense of normality gave carers a sense of control over the situation. They achieved this by developing a cohort of successful coping strategies which

meant that challenges associated with dementia could be managed with minimal upset and therefore allow them to maximise the sense of normality.

- **Chapter 6** presented results for carers. Results were discussed over two main themes of impact and coping.
- With regards to the impact of dementia, three themes were developed for carers. The first theme 'impact on their spouse' included awareness of memory associated difficulties and changes in their spouses' temperament.
- The second theme 'impact on carer' demonstrated carers' initial reactions to diagnosis, responsibility, worries/depressed and feeling trapped.
- The third theme 'impact on relationship' demonstrated carers' awareness of changes to communication and their desire to protect their spouse.
- With regards to coping with dementia, three themes were developed for carers. The first theme discussed the coping strategies demonstrated by carers such as development of positive cognitions, altering behaviours and restoring normality.
- The second theme referred to maintaining feelings of couplehood. This was achieved through existing ways of maintaining couplehood and also through the development of new ways such as spending more time together.
- The last theme 'external support' included positive and negative aspects of external support, which carers reported they had received from family, friends, neighbours and colleagues.
- The carers wanted their spouses to be happy above all else. They achieved this by developing an arsenal of successful coping strategies that allowed challenges to be met with minimal disruption to the 'norm'.

Chapter 7

Results – Couples

Having previously presented the findings for people with dementia and carers separately, this chapter now focuses on the dyads themselves and the way in which dementia has affected, and impacted upon, each couple. In taking this approach, the aim was to identify common themes facing couples rather than individuals as they met the demands of a diagnosis of dementia. Therefore, this chapter further develops this study by returning to the data and simultaneously exploring the perspectives of both members of a couple. This provided further understanding of the impact of dementia on couples and as such may aid the development of future interventions whose primary objectives are to help people with dementia and their loved ones cope with dementia.

This study has already highlighted that couples facing dementia are in a unique and positive position because they have access to two fundamentally important things – the marital relationship and everyday life – which they can use as part of their coping arsenal. This is unique to couples whereby the very essence of marriage would suggest that they know each other well, and also means that they are involved in each other's lives on an everyday level. Certainly, for some of the retired couples in this study, this meant they were in constant contact. Therefore, couples have privileges that may not be afforded in other family relationships, and this highlights the importance of exploring the couple relationship in the experience of dementia.

This chapter represents the second phase of analysis in which all of the transcripts were re-analysed on a couple by couple basis. This revealed that the primary aim of many coping strategies adopted by couples was to maintain meaningful involvement for the person with dementia. This referred to involvement in both everyday life and their relationship, and was something that couples worked hard to achieve because it helped to dispel the notion that dementia had taken over. Furthermore, when couples were successful in achieving meaningful involvement for the person with dementia, this allowed

them to enjoy a sense of normality in at least that area of their lives. The couples in this study reported on the importance of finding a sense of normality in their lives, and this may explain why the coping strategies chosen by couples focused on achievement of this goal.

This chapter begins with a discussion of couples' understanding of dementia which includes consideration of how dementia was defined by them, the role of medication, and ways of thinking about dementia for couples. This will give the reader a précis of how the ways in which couples understood dementia had an impact on the ways in which they approached and thought about dementia. This will provide a useful background for the second part of the chapter which outlines the ways in which couples attempted to cope with dementia. As outlined above, the key motivation for couples was to maintain a sense of normality and therefore the second part of the chapter will consider the three main ways in which couples attempted to achieve this, (keeping active, lessening the load, and direct discussion and support).

7.1 Couples' understanding of dementia

Couples' response to dementia was underpinned by their understanding of dementia both in terms of the disease itself and the implications for them as a couple. Although the inclusion criteria was clear that the participants of this study needed to have recognised that they or their spouse had memory problems and were willing to discuss it, terms such as 'dementia' or 'Alzheimer's disease' were not used by the researcher unless the participants did so first. This was done purposely to ensure that these terms were not imposed on participants and that they used the terminology that they were comfortable with. This adheres to one of the benchmarks for good practice when interviewing people with dementia which recommends that researchers should allow their participants to take the lead on this issue so as to avoid inadvertently causing any harm (Hellstrom et al 2007). Thus, whilst the labels that participants chose were not always accurate, they reflected the term that they had adopted. For example, the following quotes illustrate how Couple 11 had chosen to overlook the 'Alzheimer's' part of the diagnosis, instead

focusing on the fact that it was at the early stages of the disease and therefore referred to it more generically.

Interviewer: You mentioned earlier about Alzheimer's, is that what you've been diagnosed with?

Patient 11: No its cognitive memory loss or something it's called. It's not as bad as that.

Carer 11: And he straight away came out "Oh you're in the early stages of Alzheimer's" which was a bit of a shock really. You know because it's... it's classed as early cognitive memory loss... I think now. But yes that was a bit of a shock coming out at the first visit was that, but you know.

These quotes illustrate the importance for some couples of presenting a united front, in the example above by focusing on the mild aspect of her diagnosis. Other couples also used the same term to refer to 'dementia' or 'Alzheimer's' and this was particularly the case for couples who reported discussing dementia openly. However, it was also common for partners within a couple to use different terms to describe dementia, for example, one saying 'memory loss' and one saying 'dementia'. This most often occurred in couples who reported some difficulty with discussing dementia.

Although there were differences in how couples 'named' dementia, it did not appear to have impacted their level of understanding. Indeed, despite the different terms used to describe their dementia, the couples of this study generally demonstrated a good understanding of dementia and the implications for memory. For example:

PWD 5: I mean it isn't something that you can, unfortunately, that you can make yourself do. I mean you can try your hardest to remember but you can't make yourself remember if your brain says "No I'm not gonna remember that".

Carer 5: And er so, so it's progressed. Her memory was not as bad some months ago, um, like this morning I said to her "Would you take those two boxes upstairs love", "Yes, course I will", she turned round and walks off out the door and the boxes are still there. It has got to that stage...

These two quotes both indicate that this couple understands that the memory problems experienced by PWD 5 were caused by her dementia, and not something she herself was responsible for. By introducing the notion of 'stages', this suggests that Carer 5 had some understanding of the progressive nature of dementia. Indeed, this example is representative of couples in this study generally who showed a good understanding of dementia including the implications for memory.

Therefore, although the terms used to refer to dementia differed between couples, this did not mean that couples lacked understanding of dementia. Thus couples need to feel comfortable in the terms they use to describe dementia. This is highlighted by the finding that their basic understanding of dementia and its implications was essentially similar across the board. Further examples of how the understanding of dementia affected ways of thinking and coping strategies will be presented throughout the chapter.

7.1.1 Role of medication

Often couples used medication as a point of reference through which to discuss the impact of dementia. For example, several couples remarked on the positive affect of the anti-dementia medication in halting the progression of the disease.

PWD 11: I'm quite convinced that without tablets I wouldn't have been like I am now. I would have... if it's anything, going through my mothers side I would have been very difficult to handle I expect. Where as now my life is just enjoyable and I don't have to worry.

Carer 11: I'm convinced that these tablets she's on, to my mind anyway, have certainly helped putting it off a bit longer and longer, because she doesn't seem to have got worse.

These quotes highlight the tendency amongst couples to ascribe importance to the ability of medication to control dementia. Some participants had a more realistic appreciation (as shown by Carer 11 above) that the medication was acting to put off the inevitable rather than halting the progression of dementia completely. However, couples were generally keen to talk about the role of medication in their experience of dementia, and therefore, this topic of discussion could be a useful tool for couples since it provided a device around which to discuss dementia. Furthermore, it also provides a good example of Couple 11's awareness of the progression of dementia despite their use of generic terminology ("cognitive memory loss") to describe it.

Medication therefore, had a positive influence on couples' definitions of the impact of dementia particularly where they observed a marked improvement that dated from the time the medication was started. For example, Couple 12 were also sure of the positive impact of the medication to PWD 12's life, as the following quotes show.

*PWD 12: Before I was on them [Aricept tablets] I can honestly say I would sometimes cry and say "oh please God take me". And that's a wicked thing and I'd say to myself "oh don't be ridiculous think about you know, *** [daughter] and *** [husband]", but I couldn't cope. But I could cry now just at the thought of it. Once I started taking those tablets I came alive again, and if anybody disputes that and says them tablets are not worth it, for somebody that's got Alzheimer's they want to have Alzheimer's themselves to find out what it's like. I'm ever so strong about that.*

Carer 12: To the Aricept, it's virtually given her her life back. You've seen her... It's quite amazing. Alright she's steadily getting worse, but it's a very, very slow pace. So we're very fortunate.

These quotes report that the medication gave PWD 12 'her life back', which represented a strong and positive approach to dementia for this couple. This illustrates that the medication was perceived by couples to perceptibly slow the progression of dementia. This gave both members of a couple the ability to reclaim (at least in the short term) parts of their lives that they had thought they had lost.

Therefore, medication is potentially a powerful tool in the development of adaptive coping strategies if it upholds the belief that the progression of the disease had been halted, for this can give couples the confidence in the stability of their situation and therefore allow them to adjust accordingly. Medication was also commonly used as a discussion point through which couples talked about their progress in coping with dementia.

7.1.2 Ways of thinking about dementia for couples

Further to the basic understanding of dementia and its impact on memory and cognition, developing understanding also impacted on the way in which couples developed ways of thinking about dementia. For example, understanding about what the future might hold was determined by what they had learnt about dementia as well as personal experiences of people with dementia. Couples used this knowledge to develop ways of approaching dementia as the quotes below illustrate.

PWD 6: It's just one of those things, once you've got it, that's it you're never going to get rid of it.

Carer 6: My sister looked after somebody that had it, and I know what it's gonna be, so I try not to sort of dwell on it too much, too much.

These quotes demonstrate a typical response from couples whereby although they were aware that dementia was incurable, they did not want to focus on this inevitability. Couples generally felt that it was detrimental to feel too upset about dementia. This was not to say that they did not recognise feelings of sadness and loss, but more that they actively chose not to focus upon these feelings.

PWD 8: I like to forget the Alzheimer's, things sort of, not to worry about there, I can't do much about it.

Carer 8: You think it's not gonna, you know, it can't get better, it's not gonna change so it's no good being, making me ill really, by trying to, well I don't know what I was trying to do really. I was probably resenting it.

In the last quote, Carer 8 admitted to feelings of resentment which she later realised did not help her to cope with the situation. This suggests that the development of positive feelings about dementia were achieved after couples had had chance to understand what dementia meant for them and adjust accordingly.

The following quotes provide an example of two couples' desire to get on with their life despite dementia, and that given time, it ceased to take centre stage.

PWD 8: I don't know how old I am and I don't wanna know how old I am. That's nothing to do with Alzheimer's! As far as I'm concerned I've still got a lot of living to do.

Carer 8: I mean it's [dementia's] not that bad, it's just that when you talk about it, it sounds, sounds bad, but it's not bad all the time.

Carer 6: I wouldn't wish it on anybody like what he's got but when you've got it, you've just gotta make the best of it haven't you.

PWD 6: I know it's there, and, and, things like that, but I just pass it by, yeah. I, if I dwell on it, it's gonna get worse. If I, I, push it away, then it's not gonna, isn't gonna be there... So, in that case then, I'm not actually allowing it to get to me.

This response was typical across couples in this study and this way of thinking was often developed in the period following diagnosis, which was initially viewed as a negative and catastrophic event. After time and some adjustment, couples often commented that they had noticed that dementia had not affected all aspects of their life and this helped them to put dementia into perspective. Therefore, this allowed them to see that living with dementia, at least at the early stages of the disease, was not necessarily the negative and catastrophic experience they had been expecting following diagnosis. The following quotes underline this process and indicate that a certain level of acceptance allowed couples to recognise positive feelings and develop a fighting spirit.

PWD 9: I have a good life so I can't really moan.

Carer 9: No I actually feel much more positive now. You get bad days and good days, but generally I feel much more positive now.

Carer 9: Why shouldn't it happen to us I think now. It's better than it happens to somebody else that probably couldn't cope with it. And we both think now... well you know we're getting older now, chances are you're going to get something anyway

so we're both learning to accept that and if it hadn't have been this it would have been something else, something worse even.

PWD 9: It's definitely made us closer... I think it's because we help each other.

Carer 9: It's made us closer. It's made us closer and I didn't think that would have been possible but it definitely has. Because we both cherish every moment we've got together. We both do.

Thus, although couples were aware of dementia and the progression of the disease, they actively tried to focus their attention elsewhere. This was achieved by couples once they had accepted the reality of dementia including the fact that it was incurable. Several couples felt there was nothing they could do about it, and this information allowed them to focus on making the most of their situation whilst they were able to still do things. Therefore, couples demonstrated the desire to get on with their lives as much as they could.

This section has shown how couples' understanding was represented by the terms they used to describe dementia as well as by their understanding of its implications. Examples were given with regards to memory, medication and the future, but it should be acknowledged that couples' understanding of course went beyond these examples. The role of medication proved to be a popular topic within the interviews with couples being able and willing to discuss the impact of the medication on the person with dementia. Therefore, this topic may be a useful framework for discussing couples' views of how they are getting on. However, this may also reflect their experiences of clinical interactions in which they were likely asked about the impact of their medication. Therefore, this may reflect a practised discussion, but nonetheless was something that both people with dementia and carers were willing to talk about. Understanding also allowed couples to develop ways of thinking about dementia, which often lead to acceptance and a desire to get on with their

lives. Indeed, couples often reported that although they were upset about dementia, they did not want it to get in the way of them enjoying their lives. Therefore, couples were aware of the implications of dementia but tried not to focus upon this.

The remainder of this chapter focuses on how the couples in this study achieved this goal of acting on these positive thoughts and returning their lives to normal as much as they could. This will begin with a discussion about the practical ways in which couples maintained a sense of normality about their lives and how this was enhanced by their understanding of what was meaningful to them. Further benefits of the couple relationship in dementia were also found with regards to understanding their partner's reactions to dementia in context. These issues will be discussed and illustrated using examples from couples who used their knowledge of their spouse in order to determine which coping strategies were used and how they were implemented. An appreciation of the roles played by people with dementia and carers will be presented throughout.

7.2 Maintaining a sense of normality

Trying to maintain a sense of normality constituted a major motivation for couples' response to dementia, following their desire to get on with their lives. Within couples this was chiefly maintained in three key ways: keeping active, lessening the load, and direct discussion and support. All three ways will now be discussed with attention paid to the roles of each partner.

7.2.1 Keeping active

When discussing the ways in which they attempted to maintain a sense of normality in their lives, couples frequently cited keeping active as a key strategy. The following section will present examples from different couples in order to illustrate the ways in which this was manifest among the sample. This will allow the reader to see how the in-depth knowledge of their spouse allowed couples to develop meaningful ways of keeping active.

The use of routine allowed couples to ensure that they kept busy, and the everyday nature of the activities involved in these routines ensured a sense of normality for them.

PWD 7: Yes, it does [help to have a routine], yes, because I know what needs doing and what doesn't need doing and what needs washing and what doesn't need washing.

Carer 7: I've always worked on a Tuesdays we, I do the, help we do the small, small washing, what we called the small washing, er Thursdays we do the bedding and all that, that's our routine, we keep to that routine. She turn round and say that's it, bedding day today or like, smalls, different things.

The above quotes show how the use of a routine allowed PWD 7 to feel orientated in her week, and also meant that she was afforded some independence and the ability to take charge of some of the chores. Furthermore, routine enabled Couple 7 to gain some control over their life, which provided a welcome refuge from the uncertainty of dementia. This provided them with stability and security which also allowed PWD 7 to retain involvement. The usefulness of partaking in specific activities that contributed to a sense of normality was also reported by couples.

Carer 7: What we've started doing is going to the Co-op, buying some sandwiches and making like a picnic, right there on the seat.

PWD 7: We do an awful lot of walking, you know... we see a lot of people and they talk to me and they just don't know any difference you know, because it's good. We're talking and if I say something twice he'll (nudges me and laughs).

These quotes show that this approach worked well, because doing a 'normal' activity such as going for a walk brought no pressure with it to reveal the dementia, and therefore couple 7 were able to carry on as normal. PWD 7's quote also highlights the comfort she found in the shared understanding she held with her husband regarding how they dealt with her making mistakes in public. It also illustrates how her husband's sympathetic and sensitive approach to his wife has instilled a sense of confidence in her ability to partake in social activities. The following quote suggests that Carer 7 is aware of the importance of his presence.

Carer 7: She still likes to catch hold of hands while we're talking. I think she's just reassuring herself that I'm there.

Therefore, Couple 7 benefited from continuing with everyday activities, in this example going for a walk, because it allowed them some respite from dementia, since doing a 'normal' activity meant that there was no pressure or need to reveal it. The above quotes illustrate that this technique was particularly successful for this couple due to the responsive and sensitive approach of Carer 7 which meant that PWD 7 felt reassured and therefore comfortable to partake in these activities. Of course, Carer 7's presence was an essential feature of the success of this venture for Couple 7.

Furthermore, the following example shows how PWD 4's general desire to make the best of the rest of his life was made a reality thanks to his wife's efforts. For example, the quotes below show that PWD 4 possessed the will and a certain level of motivation to keep active.

PWD 4: I've had a good life, let's make good use of the rest of it, make good of the rest of it.

PWD 4: I made, make me bed, do a bit of ironing, a bit of washing or drying up... Yeah, I keep, you know, I keep myself going.

However, it was his wife who actively encouraged this activity particularly as she also held the belief that it was good for her husband to keep physically active.

Carer 4: Well he seems quite happy just to sit. I suppose I should let him sit and do what he wants, it'd probably be kinder. But I think it's not good for him to sit.

Carer 4: If he fell asleep and woke up I'd say "Come on, let's go out for a walk" or "Let's go on the bus" and he'd get up and come. It's just getting the energy to do it.

These quotes show how Carer 4 was providing her husband with the perhaps higher level of motivation he required in order to keep active and engaged in activities outside the home. Indeed, a key factor of successfully keeping active was the person with dementia taking an active interest and role in activities, and being encouraged to do so. This was most successfully achieved with regards to activities that the person with dementia enjoyed.

PWD 3: I love the gardening, I, I think it's alright the old garden. Grass wants cutting now, see, get the old machine out soon... Keep energetic. Keep um, keep busy.

Carer 3: He used to say well you cook the dinner and I'll wash up. Sometimes I wiped up, but not very often. I usually say "Do you want to, a hand" he says "No, no sit down". (laughs) I don't insist! (laughs) No, no, like I said he's a lot better than some.

These quotes from Couple 3 highlight the importance of upholding activities that held some significance for the person with dementia. In this instance, PWD 3 emphasises the regard he holds for keeping active, and the quote from Carer 3 illustrates one of the ways in which she encourages this independence. These examples have all illustrated the usefulness of

maintaining the involvement of the person with dementia in day to day activities.

Most couples saw keeping active as a joint venture in which each partner made attempts to uphold the involvement of the person with dementia. However, the following quotes illustrate how keeping active was achieved in a slightly different way by couple 5.

PWD 5: I don't like it, but I'll be quite honest I don't. Drives me mad at times, but I do my best to combat it, by doing my crosswords, by going out, by trying to keep my brain active.

Carer 5: She has to make her own way... if I start that, that I'm right by her all the time, she won't try anything for herself. She's got to think for herself. I'm not being cruel.

These quotes show that Couple 5 both put emphasis on PWD 5's ability to keep herself active and involved. From Carer 5's point of view he could be trying to uphold her independence as much as possible, essentially by ensuring that she was not de-skilled. However, it is also possible that this response from Carer 5 represents a distancing of himself with regards to the responsibilities of maintaining his wife's involvement. Indeed, PWD 5 was always a very capable woman, but if Carer 5 was distancing himself on the belief that his wife could manage dementia as she did other challenges, this may represent a lack of understanding about the implications of dementia. Thus, an understanding of how couples work and what is important to them is central to developing meaningful solutions to dementia-related challenges. Furthermore, if solutions are meaningful they are more likely to represent normality for the couple.

Other couples focused their attention on maintaining extra-curricular activities. For example, Couple 11 had always taken part in a variety of activities both individually and together throughout their lives. This couple upheld their sense

of normality in their life by keeping a fairly busy schedule of activities which reflected their lifelong involvement in hobbies and socialising.

*Carer 11: Well the way I look at it you never know do you? If you don't book things in advance you won't go anywhere... I might be gone before *** [wife] by Christmas, you don't know do you? So you've got to look to the future and enjoy yourself while you can.*

PWD 11: He does a lot of singing and I... occasionally he'll say "Come with me today" because he said "they're a nice crowd where I'm going this time" and I have been and I enjoy listening to them.

These quotes highlight Carer 11's positive approach to their lives, and also shows how PWD 11 had responded to this approach. Indeed, like Carer 7, Carer 11 was also careful to ensure that he was there to support his wife at these outings as the following quote shows.

Carer 11: She gets in a little bit of a tizz sometimes, she's not quite sure where to go and what to do, you know what I mean? I mean she sings in our church choir, and sometimes she'll forget what hymn it is or which book to pick up, you know that kind of... so I nudge her and point it out, yeah. It's silly little things like that really.

Therefore, these examples highlight how the beliefs of the carer can inform the way in which couples respond to dementia. In this example, because Carer 11 was keen to make the most of their lives, this ideal was upheld when his wife was diagnosed with dementia. Furthermore, in order to continue to uphold this, Carer 11 was careful to encourage and support his wife when they did partake in activities. This arguably enabled Couple 11 to uphold a sense of normality in their lives because they were continuing to take part in the same activities. Therefore, perhaps the level of involvement in activities is not as important as

ensuring that the person with dementia takes part at whatever level. This may explain why the two couples described here, both reported positive outcomes from the continuing involvement of the person with dementia in activities despite a reduced level of independent involvement. This idea is also supported by the following quote.

Carer 10: Like any jobs he'd once get on and do, he has to really think about it now and I have to help him with something. As we mentioned before, there was poles to put up, I did the measuring, he'd do the drilling but give him the confidence of still being able to do a job, but he just needs that support in doing it. He's still doing it.

However, not all couples had the luxury of being able to spend all of their time together if that was what they wished. In this sample, Couple 9 were forced to develop their sense of normality whilst Carer 9 worked full time. However, despite these constraints, the following quotes illustrate the success of Carer 9's attempts to instil a sense of normality for her husband.

Carer 9: I'll leave him the washing up because I know he can do that, and it keeps him busy, but he'll wash up in cold water, he won't think to wash up in hot water, so before I go to work I make sure there's hot water in the bowl, so, the washing up'll be on the side, and then he's not sure if he's actually washed that up so he'll wash it again. And it takes him so long to do the washing up, that'll probably take him all morning but that's fine, he feels he's busy.

PWD 9: I don't just sit there, sort of you know um feeling sorry for myself you know... Yeah, yeah, its surprising, I thought I was gonna get bored, but there always seems to be something to do or somebody might come round with something cos I like actually repairing things, because that's all I've ever done all my life, you know...to do things like somebody come down and

said my kettle's broke or someink like that, you know, I'm glad to do it you know.

The last sentence illustrates how important it was for PWD 9 to feel that other people had confidence in his ability. The benefits of this are twofold in that it diminishes the impact of dementia, but also that it reinforces his sense of identity because this was an activity that he had done, and done well, all of his life. The fact that her efforts were seemingly unnoticed by her husband was actually adaptive in this case because, as the quote above shows, PWD 9 felt that he was busy and contributing to their lives in a meaningful way because he was supporting his wife's traditional role in the home whilst she was at work. This subtle approach seemed to be most constructive in this case since it enhanced feelings of involvement for her husband without patronising him. Perhaps if PWD 9 had been aware that his wife deliberately left the washing up just for something for him to do, this could have had the reverse effect on him leading him to feel patronised or belittled. Therefore, whereas direct discussion within couples no doubt has its place in coping with dementia, it may also be detrimental at times where a more sensitive approach may work better, as illustrated below.

Carer 9: At the moment I'm trying to, you know, you have to try and live, as normal a life as possible, the minute he knows its affecting him, (pause) he goes downhill.

Here, Carer 9 was able to use her knowledge of her husband and recognise the importance of subtly maintaining his involvement in everyday tasks and activities, because it helped him 'feel busy'.

However, some PWD demonstrated an awareness of their partner's efforts to maintain their involvement in activities. The quote below shows PWD 7's fond regard towards her husband's input which was not at all detrimental to her overall coping.

PWD 7: We always do things together, you know... so it, it keeps my mind knowing what has to be done and how it's got to be done, you know and um if he does something wrong, I don't know if he does it purposely (chuckles) and I'll say 'Oh I'll put it straight!' or something (laughs).

Here, PWD 7 responded positively to her husband's gentle persuasion to take part in activities. Conversely, Carer 9 was careful not to let her husband see changes related to his masculinity that she perceived in him as a result of his dementia.

*Carer 9: It's destroyed him as a man and um, but we still have something special, which is good... *** [husband] was working and overnight he lost his job, and it's alright if you're retired and used to being there, but to him, you know he lost his job, they took his driving licence away from him, everything that makes him a man was taken away from him overnight.*

These quotes illustrate the importance of individualised coping responses to dementia. As the disease can manifest in so many different ways in different people, so can the impact of dementia and therefore the way in which it needs to be managed. It is positive that the couples in this study seemed to have achieved a sense of normality with regards to dementia because this suggests that the couples were able to respond to their individual needs and adapt accordingly.

Overall, these examples illustrate that couples were working towards the same goal, which was essentially to uphold a sense of normality through maintaining involvement, but the ways in which people with dementia and their carers approached it were sometimes different. In most cases the practical involvement of the person with dementia in everyday activities was augmented by the carer. Certainly, people with dementia had the desire to keep active and did what they could to achieve this, but it was often the input of the carers which enabled their partners to continue doing these and other activities.

Therefore, it could be argued that while the partners with dementia had the will to keep active, their carers provided the practical motivation to ensure that this was achieved.

Appreciating people with dementia's unique identity has the potential to be a powerful tool for adaptation to dementia. The couples in this study were particularly well placed to access this, through their intimate and often long-term knowledge of the person with dementia. In support, both people with dementia and carers in this study sought to ensure continued involvement in identity-rich activities. Furthermore, the ways in which strategies were implemented were done in ways that suited the individuals, and again, couples were well placed to know which coping responses would be adaptive for their spouses.

7.2.2 *Lessen the load*

Further to understanding which activities were meaningful to their spouse, couples in this study also demonstrated that they were ideally placed to understand the responses of their partners in context of how they had responded to stressful situations throughout their lives. Therefore, understanding for couples had an added dimension because their interpretations of each others reactions were rooted in an intimate and in-depth knowledge of their spouse. This level of understanding seemed to allow couples to cope straightforwardly with some dementia-related challenges. For example, memory-associated problems were often linked to feelings of frustration in couples, which was manifest in different ways. The following quotes illustrate Couple 12's response to Carer 12's frustration over his wife's repetitive questioning.

*Carer 12: And when I do raise my voice she will accept that I'm not raising my voice in frustration to her, it's the... her Alzheimer's that I'm getting annoyed with. And it's true, I am. I do at times. It's not *** [wife]. It's the frustration of listening to her, keep on going answering the same question.*

This quote specifies the frustration felt by Carer 12 as a physical manifestation which was his raised voice. This was not a sign of anger towards his wife per se but rather a means of indicating his frustration and powerlessness in the face of dementia. This response was regarded by his wife in context of their life together, and as such, she was able to understand her husband's reaction and reflect upon this, as the following quote shows.

PWD 12: He might be a bit fiery, it wasn't intended if you know what I mean, it was because either because he'd done so much work or... one of the other things, and men have coped with things different to women.

Therefore, the couples in this study were in a superior position because they held in-depth knowledge about their spouse which allowed them greater understanding of the responses made by their partners to the stresses associated with dementia. This is further demonstrated by Couple 3's response to Carer 3's frustration with her husband's memory loss, as illustrated in the quotes below.

*PWD 3: *** [wife] gets a bit annoyed (chuckles) cos I don't remember. I say "Well I can't help it, why is it happened to me".*

Carer 3: Sometimes I shout at him, very often I shout at him (laughs) especially if it's in the morning (laughs). No, no I do, I do sometimes argue and I think "For Christ's sake shut up woman" because it's not doing any good (laughs).

Furthermore, PWD 3 was able to frame his wife's frustration using his knowledge of her as a person and how she responds to stressful situations. This means that he doesn't take it personally when she shouts at him.

PWD 3: She would worry about anything... I say "Don't worry dear", I said "everything'll sort itself out".

Also, couple 3 were not used to having in-depth discussions, and therefore, this was not something that had changed since he was diagnosed with dementia. As the following quotes show, both partners were resigned to this.

Carer 3: Um, but I've never been able to have a good discussion with him, because he's always, left it up to me, "I leave it entirely up to you" would be his stock answer or "That's your job, get on with it" or "Get off my back for Christ's sake!" (laughs)

PWD 3: Sometimes she gets annoyed, probably because she'll, she'll speak to me and I'll just like sort of I can't, I just ignore her (laughs) or me hearing aid is not working properly (laughs). So um er, we just sit down there in silence sometimes... Yeah, she gets really annoyed sometimes with me. It er, well it's just one of those things in it.

Therefore, this is a couple who have never really 'worked together' in order to meet challenges, and as a difficult challenge (dementia) has come about, they have responded in their normal (pre-dementia) way, which was adaptive for this couple at that time.

These examples illustrate how a shared understanding of how each partner responded to the stresses associated with dementia enabled both partners to respond adaptively to their spouse, which contributed to the way in which couples managed the impact of the illness. This understanding also arguably helped couples to maintain a sense of normality because they could view their spouses' responses in context of their usual response to stressful situations. Therefore, as shown above, couples often carried on supporting each other in the same ways that they had historically.

However, couples also typically used this understanding of their partners' reactions to make additional attempts to support each other in order to fulfil their goal of getting on with their lives. The primary intention of these attempts was often to lessen the load on their partner and therefore, such attempts were often made without their partners' awareness. For example, Couple 1 were both aware of the fact that Carer 1 sometimes felt frustrated over her husband's dementia. Her frustration is illustrated by the following quote.

*Carer 1: You know, I, I get irate at times um, he just sits there and I say '*** can you put the tables away?' 'Oh yeah, why didn't you ask?' (laughs)*

In the interviews, PWD 1 described his efforts to minimise his wife's frustration, which he felt he achieved by agreeing with his wife even if he did not actually agree. His response is embedded in understanding of the difficulties of dementia, his understanding of her responses in their historical context, and also his desire to protect his wife from as much as he could.

PWD 1: I've contented myself with the fact that I'm gonna agree with whatever she goes along with.

PWD 1: Just lately there are times when it comes to, shall we say a disagreement um but out of all that um, rather than it being an issue, you know a continuous issue... I would tend to stand down.

Therefore, PWD 1 was using his power to still do what he could to improve the situation. Similarly, but unbeknown to her husband, Carer 1 was also making efforts to appease the situation because she was aware of the impact of her frustration on her husband.

Carer 1: I'm more aware of the nagging situation than I probably was before... somebody's alright mentally they can

*stand a bit of nagging, but I mean if they're like *** [husband] I don't like... I try not to... nag.*

Understanding the implications of dementia allowed this couple to understand why Carer 1 was feeling frustrated and also to therefore make informed choices about how best to cope with the situation. The following quote provides further evidence of PWD 1's willingness to please his wife.

PWD 1: I won't say that I'm looking forward to it [respite] but I probably will like it when I get there... You know, I mean I'm prepared to accept it with open arms.

This acceptance and willingness to attend respite despite it not being his preferred option, shows that PWD 1 was able and willing to put his wife's interests before his own. Therefore, with these actions, both PWD 1 and Carer 1 were trying to lessen the load on each other.

Lessening the load was also found in other couples who did not appear to discuss their true feelings about dementia, but instead put on a brave face in front of their spouse. For example, the following quotes show how Couple 6 both have some insight into the impact of dementia on each other, although it was not something that they seemed to explicitly discuss.

PWD 6: They [his memory problems] probably have [affected wife], I don't know. She never says.

*Carer 6: I will say to, about *** (husband), although he's got it, he never ever moans and says "Why me?" or never, he don't sort of get angry over it.*

Indeed, despite presenting a positive façade in front of each other, this couple both independently used the same term to describe what they really thought of dementia.

PWD 6: Don't you ever get Alzheimer's, honestly, it's terrible.

Carer 6: He ain't bad, I just feel sort of sad, it's a terrible thing isn't it.

However, rather than reflecting any problem with this approach, these quotes highlight the attempts of spouses to protect one another from the worst of it. For some couples, this simply reflected their lifelong approach to problem-solving, and certainly for Couple 6, there were no negative connotations at the time of the interviews. Indeed, the use of these more subtle methods of coping were popular among this sample and did appear to have some efficacy for minimising stress on their spouse. Couple 11 provide further evidence of this as they both made attempts to protect each other.

PWD 11: Emotionally you're irritated because you know you've had to go and ask again because you've forgotten and have it written down and things like that...I don't like being like this and I hate it when I have to repeat myself, and when he says "you've just told me that" I could kick myself, but you've got to learn to live with it haven't you? There's nothing you can do.'

PWD 11: I do wish I didn't need to have to go and ask him again, but... as I think he must get fed up with it, but he's so patient and he doesn't seem to mind.

These quotes illustrate that PWD 11 made attempts to remember things herself such as writing them down. However, she also recognised that this approach did not always work and sometimes her memory loss was evident. At these times she also noticed and appreciated her husband's patient response. The following quote from Carer 11 suggests that he was also aware of this importance of his response.

Carer 11: She gets things mixed up a little bit... And she says things have taken place that haven't... I'm trying to be very diplomatic.

These quotes show how Couple 11 were both trying to protect and support each other, and PWD 11's quotes illustrate the importance of patience in carers. This was particularly pertinent for PWD across this sample because being at the mild stages, they usually realised the impact of dementia on their spouse and appreciated that it was sometimes difficult for them to cope with. Therefore, these quotes show how important a spouse's reaction can be. Here, the carer's patience and kindness meant that the negativity and anxiety felt by his wife was somewhat quashed. Had he responded less sensitively, the danger is that the person with dementia may feel defined by their dementia and the things they struggle with as opposed to the things that they do well. Therefore, a sensitive approach to communication within couples which involves kindness, patience and reassurance was often a central part of maintaining the sense of normality that couples coveted.

However, some quotes suggested that at times it would be useful if couples were aware of the efforts made by their partners. For example, PWD 5 made a concerted effort to work things out for herself in order to avoid, as she saw it, burdening her husband further.

*PWD 5: I try not to ask *** (husband) too much. I try to look at the calendar first so that I know what's happening. well he's got enough on his plate without me, I mean, without worrying, you know, if I can remember and do it and go there.*

However, the following quote suggests that Carer 5 was unaware of the efforts his wife made in order to go about her daily life without his input.

Carer 5: It affects us in the fact that I have to think for both of us now. I have to remember what day of the week it is, I have

to remind her that she needs to wash her hair and she needs to have a bath.

Therefore, in this case PWD 5's efforts were made with the desire to reduce burden on her husband and this meant that these activities were purposely done without his knowledge. This occurred within a number of couples and whilst this was done with the best intentions, it meant that carers were often not aware of their spouses' efforts.

As shown above, carers also made efforts to lessen the load on their partners, and so too was this done stealthily in order to maximise the affect. However, it did often mean that there were discrepancies within couples with regards to the perceived impact of dementia on the carer. For example, the quote below suggests that Couple 9 had adjusted well to the changes imposed by dementia.

PWD 9: It [him not working] doesn't really effects things, my wife does, sort of looks after things like that now so you know (coughs) I'm used to it and she's used to it.

However, this quote sheds little light on the reality for Carer 9 who had been forced to suddenly become breadwinner, housekeeper, and daily planner since her husband had been diagnosed with dementia.

Carer 9: Everything, everything, and obviously you know, I, I'm not only working, trying to keep the house up together, supporting him and being happy with him, and cheerful for him, um, and, keeping him positive, um, (pauses) sometimes I don't know whether I'm coming or going, and sometimes, that can get you down, and the biggest thing that gets me down is being cheerful, and positive, because sometimes I wanna scream, and say, (shouts) "I'm not positive!"

For Carer 9 and many other carers, this is the way that they wanted it to be, with minimum stress on their spouse, in order to uphold their goal of keeping them as happy as could be and therefore maintaining a sense of normality. Two further examples are shown below.

Carer 2: [things have changed] because of his lack of confidence and motivation, I have to fall in with what he really wants to do.

Carer 10: I try and stay calmer so it doesn't upset him.

These quotes again highlight the importance of the knowledge held within the couple relationship in determining how carers choose to alter their behaviour to best suit their spouse. They also illustrate the difficulty facing carers whereby discussing certain issues with their spouse might contradict the carefully constructed sense of normality that they were working hard to maintain. Reluctance to engage in discussion was indeed a prominent feature of carers' coping efforts. Carers often had valid and important reasons for not wanting to discuss issues, and essentially, they made these decisions with their spouses' best interests at heart. Therefore, this underlines the importance of a sense of normality for carers. For example, the quote below illustrates how carers often felt unsure as to whether their spouse was ready to discuss the implications of dementia.

Carer 9: We haven't come to a point of what if, because he's not ready for it, (pauses) I don't think, he can cope with that emotionally.

Carer 8: I can talk to him about things but I have to pick my moments.

However, this stance also had implications for the carer because it meant that they lost the ability to confide in their spouse, which may contribute to feelings of loneliness (as discussed below). Furthermore, carers often tried to minimise

the impact of dementia, by taking on more responsibilities and presenting a positive face to their loved ones. Whilst these actions arguably help the person with dementia to adjust, they can raise further problems for both partners. For people with dementia, their carers' well intentioned attempts to help them may mean that their carers do more for them than is necessary. This can lead to increasing dependency on the carer due to a resulting lack of confidence in their abilities. This issue was one that several of the couples were aware of, and often they worked hard, carers in particular, to ensure the continued involvement of the person with dementia (as shown earlier in the chapter). For carers who were reluctant to discuss issues with their spouse for fear of contradicting the very impression they had worked hard to achieve, the implications of this were that they lost a confidant. Therefore, these carers were willing to put the needs of their partner before their own.

Often carers were also willing to spend their time predominantly with their spouse at the expense of their own spare time. As shown earlier in the chapter, this level of interaction was beneficial for the people with dementia because it instilled a sense of confidence in them particularly at social gatherings. The importance of having company is shown in the quote below.

PWD 10: It's nice being with people. I think I would be a hundred times worse off if I was on my own... Because it would give you too much time to think. You know, and be lonely.

Carer 10 was aware of the importance of her husband being with people and strove to see that her husband kept busy, both practically and socially. However, despite all of this input, carers often described feeling quite lonely as the following quote shows.

Carer 10: Coz you can feel... although you're... we've got a good support network, you can feel quite alone sometimes.

It is plausible that feeling responsible for everything only compounds the feeling of being alone, because whereas carers would have been able to consult their spouse previously, this had become less appropriate as their spouses were less and less able to contribute as they once had. Perhaps this also explains why carers often reported wanting a physical break from their spouse because this allowed them to have a real break from responsibility, if only for a short time.

This section has shown how understanding of the impact of dementia on their spouse allowed both partners to alter their behaviour in order to lessen the load on each other. Therefore, an understanding of the impact of dementia allowed couples to make allowances and compromises which served to uphold their main goal of getting on with life. There was no right or wrong way for couples to lessen the load on each other. For example, within some couples, these activities were undertaken without their spouses' knowledge, and in other couples, both spouses were aware of the efforts they each made. Whether partners knew or not was more a reflection of them as individuals and a couple, rather than indicating success or failure to lessen the load. Indeed, most attempts to lessen the load were successful and as such these strategies formed a major component of many couples' overall coping effort.

7.2.3 Direct discussion and support

Subtle attempts to offer support within couples were certainly adaptive and held an important role for overall coping. However, couples also partook in more direct forms of support, primarily in the form of discussion. This part of the chapter will first illustrate why this kind of support was efficacious and desirable in couples before offering examples of couples who utilised direct discussion to successful outcomes.

Feelings such as shock and depression were commonly cited by couples following diagnosis, and with this couples also experienced a certain level of uncertainty about what dementia meant for them as a couple in the present and in the future. As couples began to adjust to dementia, they often

developed shared meanings with regards to the implications on their lives. For example, the following quote illustrates how Couple 1 responded to PWD 1's fears that dementia meant that his wife would leave him.

Carer 1: He was frightened of me leaving. I said "whatever gives you that idea? In all these years, why would I start now?" He said "Well you won't leave me will you because I do love you?" I said "I love you, it's silly, you know I do" He said "Yeah but I think the world of you" and I said "Well I think the world of you"...but he does say it quite often.

This quote is important because it shows that by airing his concerns PWD 1 then allowed Carer 1 to reassure him. Without this discussion Carer 1 may have been unaware that her husband felt that way. Taking this further, an earlier part of this chapter showed Carer 1 talking about feelings of frustration with regards to her husband's memory loss, and PWD 1's resulting amiability to go along with her in order to reduce that frustration as much as possible. It is possible that these discussions, which helped to reiterate their position as a married couple willing to stand together against dementia, gave PWD 1 the motivation to act in his wife's best interests because he had the knowledge that she still loved and supported him despite getting frustrated sometimes.

Carers also reported needing reassurance and emotional support from their spouses. The following quotes from Couple 7 illustrate the benefits of carers seeking and receiving support in the form of direct discussion.

Carer 7: I try to you know, if she's, if I wanna discuss you know, our love life, how we used to be and what we're like. Oh she, we still chat and talk about, she's like, she turns round, she says "As long as I've got you here" she said, "I'm here and I shall love you".

PWD 7: I can tell him anything, you know, and he's marvellous. Yeah, we never keep anything from one another, neither of us.

These quotes show that carers sharing concerns with their spouses can potentially achieve two things: first, by sharing their problems this could encourage people with dementia to do the same, and secondly, confiding their problems can act as a springboard for people with dementia to provide some valid and valuable emotional support. Thus, this sharing of vulnerabilities therefore allowed both partners to retain roles of support within the relationship. This may be especially important in mild dementia when the amount of practical support people with dementia are able to supply, may be deteriorating. The following quotes illustrate an example of a PWD giving his wife emotional support and how he still feels duly qualified to provide this.

*PWD 9: I mean say it was a funeral then that sort of thing I would stay with *** (wife) you know if it was like one of her relatives or something I would stay with her and make sure she was alright.*

The importance of this emotional support was also vocalised by Carer 9 when she was asked about whether she felt emotionally supported by her husband.

Carer 9: Oh yes. Terribly so which is lovely. Yeah I still need him emotionally and all the things that used to be. Yeah so getting all that.

Therefore, despite Carer 9's attempts to lessen the load on her husband (as shown earlier in this chapter) she felt that it was important that he continued to provide her with emotional support.

Some couples really benefited from discussing issues, particularly when partners were willing and able to listen to each others' point of view and alter things as were necessary. The following quotes provide an example of how

this worked in Couple 8. The following quote illustrates the importance for PWD 8 that his wife could appreciate his point of view.

PWD 8: If I can get my partner, my wife, to look at it the same way I look at it, then it's just a problem and I know there's no actual, you can't take medicine and it'll make you better, and if this is what it is, this is what we're gonna have to live with.

This quote suggests that PWD 8 was keen to face up to his dementia and not to let it take over their lives. Indeed, he was aware of the pitfalls of dementia-related frustration within couples and was keen that they did not fall victim to this.

*PWD 8: I've read books and things about it, where there's a husband and wife where one can get a bit annoyed with the other one, er, because of this attitude. But, ***'s (wife's) very patient and can understand things and we've sat and talked. I've explained to her things like 'I told you that' and I'll say "**** (wife), try and use other words than I told you that. Can't you say to me, Didn't I tell you that? So you're asking me the question".*

So, PWD 8 took an active role in encouraging his wife to talk to him in certain ways. This approach worked well for this couple, and allowed Carer 8 to acknowledge that whilst it was not always possible to remain patient, she would try her best.

Carer 8: If I've told him something and I've told him something that's like two or three times, eventually I say "I told you that before", which probably isn't good thing to say. Then he gets a bit, you know "Well you know there's no point you saying that to me, you know, you know". So I try not to say "I told you", I say "Don't you remember?" We talked about that this morning.

This approach worked well for couple 8, particularly due to the gracious way in which Carer 8 altered her behaviour in order to appease her husband which meant that together they improved their understanding of coping with dementia. PWD 8 was pleased with the ways in which his wife attempted to adapt her behaviour because he felt validated, that his views were important, and appreciated her making an effort.

PWD 8: She does say "What do you think of this?" you know opposed to "We're gonna do this". You know, it's always (pause) left open for, for discussion, whatever it is, you know, even to, what we're gonna have to eat.

These kinds of discussions also gave couples the chance to discuss things that may not be realised otherwise. Some of the people with dementia described how dementia made them feel more sensitive towards any intonation that they were less able. For example, noticing that their carer put their clothes out for them each day even if this was something they had always done. This was something that the carers may not necessarily be aware of if it was not discussed within the couple. Therefore, there is the danger that carers may inadvertently carry on with actions that contribute to the person with dementia's feelings of inadequacy if these things are not explicitly discussed.

Further to being able to discuss important issues, the ability to joke with one's spouse was important for some couples. For example, the following quote from Carer 8 shows how making affectionately teasing comments can contribute to a sense of normality in the relationship particularly when PWD 8's performance on some tasks may be a sensitive subject.

Carer 8: He usually takes her [the dog for walks] now. And he, he sort of meets people going around the same walks, so he, it's usually the, the like there's a couple of ladies down from us on their own, they've got dogs, and they all have a good old chinwag. He said "Oh they don't half talk some rubbish" I said (laughing) "Well you're just as bad as them!"

This activity restored a sense of normality for Couple 8 since it allowed Carer 8 to make jokes at her husband's expense which because they were made affectionately they were taken that way by PWD 8. This is juxtaposed to his feelings of inadequacy linked to his wife putting his clothes out for him, about which he would not have been able to joke. Therefore, being able to undertake both everyday discussion as well as discussion about specific issues is conducive for couples in that it helps restore feelings of normality within their lives as far as practical activities, but also that it can help restore balance within the relationship.

Couple 10 provided several examples of adaptive communication and discussion through which each partner was able to vocalise their thoughts and concerns. One example of this was the way in which they discussed PWD 10's low mood which was quite a feature of their experience of dementia as the quote below shows.

PWD 10: You try to forget about it but you can't forget, it's not something you forget. You've seen what's gone on before you as well it's.... you know, it's... it can be depressing and I suppose maybe that's why I do get a bit depressed now and then you know.

This quote refers to a close family member whom PWD 10 had observed throughout the different stages of dementia. PWD 10 felt that this level of awareness about what might lay ahead was counterproductive for him because he found it difficult to put those thoughts to one side. The quotes below show both the awareness and understanding about this issue within Couple 10, and also how they dealt with it.

PWD 10: She knew this morning I wasn't right when I got up, you know...She keeps saying "look on the positive side of..." which I try to do.

Carer 10: Well this morning... I knew something was wrong straight away and I asked him if he was alright and he said "yes", and I said "you're not, now come on tell me" because I find it's better for me and for him if you can talk about why you're feeling not right. And he said "I just feel really depressed this morning and I could cry" and I could see he was on the verge of tears, so I just chat to him if you like. Change the subject sometimes, it just depends. Sometimes he needs a hug if he does break down, but we managed to sort of talk round it this morning and he just gradually as the day went on got better.

This approach worked well for PWD 10 particularly because his wife was confident that she knew which approach would work best on any given day. Therefore, PWD 10 would sometimes be encouraged to talk about his feelings and other times, Carer 10 seemed to be aware that her husband would benefit more from some sort of distraction. Furthermore, it was because Carer 10 understood why her husband felt depressed about his family member that she tried extra hard to keep him both physically and mentally occupied in order to minimise his depression. Of course, this rather intense level of input also impacted Carer 10 meaning that she often felt tired.

Carer 10: I find I'm getting more tired now because I'm so busy keeping him occupied to stop him thinking about it I get quite exhausted. Yesterday evening was a good example; I was so tired I just couldn't do that game with him any more, I just said "I'm sorry I'm going to go and have a shower, I've had enough" because I was just so tired.

As this quote suggests, Carer 10 was one of the few carers in this sample who felt able to discuss these sorts of issues with her husband, and for this reason, she reported feeling supported by him. Like Carer 9, it was important for her to feel that she could rely on her husband's emotional support, as the following quote shows.

Carer 10: I did say to him the other day "I'm not Superwoman, I can't be on top all the time". I said "you've got to understand that that I have off days occasionally as well" which he said "yes I know" but I think you have to remind him of that now and again... I think you've just got to remind him now and again of things because he... he doesn't ignore it deliberately, he just forgets I think. So you remind him and he's ok. He's alright about that.

Couple 10 benefited from making discussion about feelings part of the day to day routine. This appeared to be a constructive way in which some couples overcame the discomfort involved with discussing potentially tricky issues. The following quotes illustrate how this approach meant that both partners felt that they were tackling dementia together.

PWD 10: We try very hard to counteract all these type of things you know, we do between us and sometimes we don't always agree but most of the times we... we do.

Carer 10: I said to him it helps me to understand better how he's feeling if he can explain to me what may have triggered it [feeling depressed] or... and he may not know what's triggered it, but sometimes he does. And I find it easier if he can talk about it.

Therefore, when these issues were discussed within couples, the outcomes were generally positive. This was because many couples reported the importance of maintaining a culture of emotional support, and direct discussion was a very successful method in achieving this. The ability for couples to make use of direct discussion as a coping strategy was linked to their premorbid use of discussion within the relationship. For example, some couples reported difficulties with communication even on a day to day basis, and for these couples, emotional support was often evident in more subtle ways such as

those seen in the lessen the load section. However, direct discussion is important as a coping strategy because it can potentially deliver reassurance, patience and kindness, as well as allowing couples to be clear about any concerns they have and openly develop shared ways of dealing with these problems. Direct discussion was particularly successful when this level of discussion became an everyday occurrence, because then it became part of the routine and less of a serious event.

7.3 What indicated successful coping for couples?

Of course, dementia brings with it a number of challenges with regards to everyday life. Couples in this study demonstrated their awareness of these challenges and also described the ways in which they attempted to overcome them. Again, the unique relationship between husband and wife allowed couples to use their knowledge of their loved one in order to ensure that meaningful solutions were found and implemented in ways that best suited the individuals within each couple. The goal which drove most couples to cope with dementia was to get on with their lives. This was done primarily by aiming to maintain some level of normality in their everyday lives, and the chapter so far has illustrated the ways in which this was attempted by couples. Furthermore, several couples were confident that they had achieved a sense of normality.

It is interesting to note that couples by no means denied that dementia existed or that it caused unique challenges or problems. In fact, it was the ability to accept these things and put them to one side that enabled couples to focus on involvement in activities that allowed them to achieve a sense of normality. For example, PWD 9 was describing an incident (where he forgot where he was going when he boarded a bus and was touched by the driver's sensitive approach to him struggling to remember) and said that despite those sorts of occurrences, life was essentially normal.

PWD 9: Apart from that, you know, it's a sort of normal life.

This was reiterated by Carer 9, who felt quite positive about the future given that they had responded so well following the initial shock of his diagnosis.

Carer 9: You do have a few problems now and then... But our lives generally seem pretty familiar [compared] to what it was before.

Carer 9: Well at the moment it's looking good, I mean I can see us being like this for quite a long time... Yeah, and back to normal almost, which is good. That's the way I feel at the moment whereas before I thought oh god it's going to be all down hill, you know, I can see us going like this now for a few years.

Similarly, Couple 11's desire to instil a sense of normality in their day to day lives meant that although Carer 11 acknowledged that things were not normal per se, they were as normal as they could hope to be.

Carer 11: Well they're [things are] not normal no. As we... before this... no no as before she developed this problem, no. No. Not as normal as they were then, but as normal as can be yes. It hasn't disrupted our life at all really...

Furthermore, Carer 10 felt that they were fairly successful at achieving a sense of normality to the extent that not even close family members had realised the extent of the problem.

*Carer 10: Well you carry on as normal. Ok we have some abnormal days but we mostly carry on as normal, and there's quite a few people who don't even realise that ***'s [husband's] got a problem. In fact even our own children probably don't realise the extent of some things because they don't... they're not there long enough.*

A sense of normality was eloquently summed up one participant who made the observation that dementia was no longer the first thing on their mind when they woke in the morning and did not permeate every waking moment. This suggests that they had somewhat allowed dementia to become part of normality, and to let other things take over such as routine chores or hobbies, and that these things have become the focus of their thoughts and attention. Therefore, perhaps adhering to a routine and engaging in activities that are meaningful and enjoyable helps to solidify feelings of normality. In support, there was certainly evidence among the transcripts that engaging in 'normal' activities was beneficial to couples facing mild dementia, as seen earlier in the chapter. This also allowed couples to focus on the parts of their lives that most reflected this sense of normality such as involvement in activities, and pay less attention to areas of their lives which were affected by dementia such as inability to work.

7.4 Summary of Chapter 7: Results for Couples

This chapter has illustrated how couples understood the implications of dementia and how this impacted their ways of thinking about dementia. Generally, couples understood what dementia meant for them and this allowed them to focus on getting on with their lives in the best ways possible. Fundamental to this drive was the motivation to maintain a sense of normality in their lives. This came in response to feelings of shock, disbelief and upset following the diagnosis even if there was a family history that made couples aware of the likelihood of the diagnosis. Couples responded by incorporating these changes to their abilities and plans for the future in order to create a new sense of normality. With understanding at the centre of this motivation, this meant that normality was not sought or achieved at the expense of reality. Couples were aware of the problems they faced related to dementia but were able to see past these problems and come to view life as basically normal with some added difficulties. Therefore, although their life as a whole did not represent normality for them, certain aspects of it did and it was often these that they focused on.

This chapter outlined the three main ways in which this was achieved: keeping active, lessening the load, and direct discussion and support. With regards to keeping active, couples often concentrated on keeping up with activities that were important to the person with dementia's sense of identity, so as to enhance their sense of self in the face of unsettling changes related to dementia. Within this sample, the carers played a fundamental role in ensuring that the person with dementia maintained involvement in such activities. Whereas the person with dementia often demonstrated the will to keep active, it was often the carer who made this a reality. Furthermore, the carers showed that they were well placed to provide input because they understood the ways in which their input would be best received by their spouses.

The second way in which couples attempted to maintain normality was to lessen the load on each other. This often occurred in response to shifts in their historical roles and responsibilities as a result of dementia, the impact of which couples often tried to minimise. Couples' unique knowledge of their partner including how they respond to stressful situations allowed couples to protect each other in appropriate ways such as people with dementia trying to reduce burden, or carers making sure that their spouses felt useful. Furthermore, knowledge of their spouse allowed couples to go about this in either subtle or conspicuous ways according to which would best suit the situation and the person. Both methods were successful in lessening the load among couples, and this therefore formed a significant part of couples' coping strategy.

The final way in which couples sought to maintain a sense of normality was direct discussion and support. This chapter outlined the importance of emotional support for couples and how this was achieved in terms of direct discussion. Certainly, those couples that felt comfortable to discuss their concerns benefited from this exchange especially when such conversations became commonplace. This helped to ensure that the seriousness of discussing dementia-related issues was somewhat diminished, and it also allowed couples to openly develop shared ways of dealing with these issues. Furthermore, discussing issues with their spouse allowed both partners to offer their partner some emotional support. At a time when people with dementia

were reporting a decline in roles and responsibilities, the ability to provide worthwhile emotional support to their spouse could be important to how valuable they felt. However, some couples reported difficulties around direct discussion because they did not want to contradict an already compromised sense of normality by further outlining problems and changes. This response was found to be adaptive in some couples, although caution should be heeded because lack of direct discussion may limit the opportunities for understanding to be shared within couples, and therefore hinder the adoption of further coping strategies.

This chapter has illustrated the fundamental role that carers played in the overall coping process by supporting, encouraging and providing practical and emotional assistance that ensured their loved one's continued involvement. Although these efforts were often difficult for carers to uphold, the success of these efforts held primary importance for carers who often cited their spouses' happiness as their key motivation. Therefore, this study highlights the incredible compassion offered by carers, and how this can shape the experience of dementia for couples. The need for carers to support their spouse was overwhelming, borne out by their continuing efforts despite the often substantial difficulties this created.

The next chapter will discuss these findings in relation to the literature and make recommendations for practice and further research as well as acknowledging the limitations of this study.

- **Chapter 7** focused on the dyads themselves and the way in which dementia has affected, and impacted upon, each couple.
- Results were discussed over two main themes of couples understanding of dementia and maintaining a sense of normality.
- Within understanding of dementia, the first theme addressed the 'role of medication' in couples' experiences of dementia.
- The second theme discussed the 'ways of thinking about dementia for couples', in which the desire to get on with their lives and regain a sense of normality was key.
- Within maintaining a sense of normality, the first theme 'keeping active' presented the ways in which couples used their knowledge of each other in order to ensure continued meaningful involvement in activities. This theme demonstrated the role of the carer in ensuring that this was achieved.
- The second theme 'lessen the load' illustrated how couples again used their knowledge of each other to alter their behaviour in order to lessen the load on their partners. This activity was conducted by both people with dementia and their carers usually without the knowledge of their spouse.
- The last theme was 'direct discussion and support' in which the benefits of direct communication were outlined. Importantly, this allowed couples to engage in emotional support.
- Generally, couples understood what dementia meant for them and this allowed them to focus on getting on with their lives in the best ways possible. Fundamental to this drive was the motivation to maintain a sense of normality in their lives. With understanding at the centre of this motivation, this meant that normality was not sought or achieved at the expense of reality.

Chapter 8

Discussion and conclusion

This chapter will discuss the results of this study in the context of the literature. The focus of this chapter is on couples, and will identify how this thesis has contributed to the body of knowledge aimed at understanding the experience of dementia for couples. This will be done by drawing on findings from all three results chapters (People with dementia, Carers and Couples).

8.1 Purpose of study

The introduction chapters of this thesis illustrated the challenges faced by couples in which one partner has mild dementia, but also highlighted the importance of this relationship with regards to coping with dementia. However, recent systematic reviews have called for increased knowledge of the caregiving dyad in dementia, with equal credence afforded to both people with dementia and their carers in research studies. Therefore, this thesis aimed to address how people with dementia and their spouses described the experiences of dementia and their attempts to cope with it.

8.2 Research question

The research question for this thesis was ‘How do people with dementia and their spouses describe the lived experience of dementia?’

Within this there were two main objectives: First, how do people with dementia and their spouses describe the impact of mild dementia on their lives and relationship? Second, what coping strategies are employed by people with mild dementia and their spouses?

8.3 Discussion

It became clear that couples described the lived experience of dementia as a process involving a number of stages. This incorporated the understanding

that dementia is a progressive and degenerative condition and therefore, that their experience of it would be ever evolving as opposed to static. Although couples defined the very beginning of this process as the time they first developed suspicions that something was wrong, undergoing formal assessment and diagnosis at the Memory Clinic was described by most as the point at which they really began to associate dementia with themselves. They described the feelings they had experienced around this time, such as shock and sadness as well as relief. Whilst they accepted that these feelings were appropriate responses to the news of their diagnosis, the next stage of the process involved couples coming to terms with the news. The main motivation within this stage of the process was a desire to get on with their lives, and indeed, couples did not want to focus on dementia, but rather to regain a sense of normality which enabled them to take control of their lives rather than feeling overwhelmed by dementia.

That the experience of dementia can be represented as a process is well accepted in the literature with regards to people with dementia as individuals (Cohen et al 1984, Keady and Nolan 1994, Kitwood 1997, Bender and Cheston 1997, Clare 2003) and carers as individuals (Nolan et al 1996a, Clarke 1999, Perry 2002, Sandberg and Eriksson 2007), as well as couples (Wuest et al 1994, Vernooij-Dassen et al 2006, Daniels et al 2007, Hellstrom et al 2007). These models present chronological stages similar to the ones found in this study. Thus, it is likely that the experience of dementia for those involved can be represented by at least three discrete periods of pre-diagnosis, around-diagnosis and post-diagnosis.

This thesis is most concerned with the 'around diagnosis' and 'post-diagnosis' phases because of its focus on the lived experience of dementia. It is important to acknowledge the feelings associated with the 'around diagnosis' period, particularly as these feelings often provided the motivation for overall coping efforts. For example, couples in this study reported that in response to the shock of their diagnosis, they wanted to get on with their lives, to regain a sense of control and normality. This desire is arguably a natural response to something which had upset the balance of normality (Robinson 1993, Kralik

2002, Brown and Roch 2010, Hayes et al 2010). Therefore, people with dementia and their carers, both as individuals and dyads, almost automatically, sought to redress the balance that had been threatened by dementia.

This action is represented in the models cited above. For people with dementia, examples can be found in Cohen et al's (1984) 'coping' stage, Keady and Nolan's (1994) 'surviving' stage, and in Clare's (2003) 'trying to explain the changes' and 'attempting to adjust to the changes' stages. For carers, examples can be found in Nolan et al's (1996a) 'taking it on' and 'working through it' stages, Clarke's (1999) 'normalisation' stage, and in Perry's (2002) model of how caregiving wives 'take on responsibilities', 'rewrite their husband's identities' and 'construct a new daily life'. For couples, examples can be found in Wuest et al's (1994) 'holding on' stage, Sandberg and Eriksson's (2007) 'taking on new roles' and 'learning to live with them' stages, and Hellstrom et al's (2007) 'sustaining couplehood' and 'maintaining involvement of the person with dementia' stages.

Therefore, the findings from this study confirm the suggestion in the existing literature that individuals and couples facing dementia make an effort to adjust to dementia, often by attempting to regain a sense of control and normality (Brown and Roch 2010, Hayes et al 2010). Thus, there appear to be similarities between models developed to explain the way in which people with dementia and carers of people with dementia respond to a diagnosis of dementia. However, there is a lack of research into how both partners simultaneously contribute to the overall experience of dementia for couples. Perry (2002) was one of the first researchers to acknowledge that the role of husband/wife was central to the adaptation process. However, this model was primarily aimed at understanding caregiving as opposed to care-receiving or how couples adapted together. Furthermore, of the models cited above for couples, only one was developed where both people with dementia and carers were equally involved in the research (Hellstrom et al 2007). Recent research acknowledges this problem and suggests that the only way to improve understanding of the experience of dementia for couples is to include both people with dementia and their carers directly in research (Davies and Gregory

2007, Hellstrom et al 2007, Daniels et al 2007, Quinn et al 2008, Braun et al 2009). Furthermore, the results of this study support the idea that if the aim is to further understanding into how dementia is experienced within couples, it is not enough to conduct research on people with dementia separately to research on carers. For example, although the results chapters for people with dementia and their carers' in this thesis were structured using the same two themes (impact and coping), the content was often quite different. In fact, it was only in the couples' results chapter that the experience for couples, and how each individual contributed to that experience, really came alive. Within this, it became apparent that whilst all couples were coping in their own way, some couples shared narratives regarding their experiences, and others viewed things slightly differently. Therefore, this thesis has added to the literature by providing an insight into the lived experience of couples facing dementia not least by ensuring that people with dementia and their carers were equal contributors.

The discussion of findings will be structured in order to illustrate how this thesis has addressed its overall aim of understanding the lived experience of couples facing dementia by addressing each of the key research questions in turn. Therefore, it follows the structure of the thesis thus far by focusing first on the impact of dementia for couples, and then on how couples attempted to cope with it. Although the discussion focuses on couples' experience of dementia, evidence from all three results chapters will be considered. This will help illustrate the unique findings gained from simultaneously exploring the perspectives of both members of the couples.

8.3.1 How do people with dementia and their spouses describe the impact of mild dementia on their lives and relationship?

Although time since diagnosis for participants in this study ranged from 9 to 67 months, both people with dementia and carers were able to give retrospective accounts of their experiences of diagnosis and beyond. Although many of the couples in this study reported suspicions about dementia, their understanding of dementia as a disease and also what it meant for them really began when

they received their diagnosis. This is in-keeping with research by Pinner (2003) who found that only 28% of people who were attending a memory clinic had insight into the fact that they may have dementia. The couples in the present study had all been through a memory clinic and undergone the necessary assessments, but despite this most couples still reported shock and disbelief when the diagnosis was actually given. Moreover, even those individuals who did report suspicions that they or their spouse had dementia (usually due to family history) reported the same feelings of shock when the diagnosis was disclosed. Many carers described the diagnosis as the first time that they were no longer able to deny what was happening. This supports previous research (Kralik et al 2000, 2004, Lewis 1998), and suggests that the presence of suspicions about dementia coupled with shock at the diagnosis indicates that couples often use denial in the phase leading up to diagnosis. This may also explain the low numbers found by Pinner (2003).

Once the diagnosis was actually confirmed, and the ability to deny or hope to the contrary was dashed, the couples in this study described feelings of anger, sadness, loss, grief and a loss of control. These findings are supported by Vernooij-Dassen et al (2006) who interviewed couples two and twelve weeks after receiving a diagnosis of dementia, and found similar feelings were reported by their sample. Similarly, research that has addressed the experiences of individuals facing dementia supports the view that people with dementia experience feelings of depression, anxiety and vulnerability (Burns et al 1990, Chatterjee et al 1992, Welleford et al 1994, Garner 1997), and carers experience anxiety, anger, helplessness, loneliness, depression, stress and guilt (Eagles et al 1987, Rabins et al 1990, Jones and Martinson 1992, Ott et al 2007, Laakkonen et al 2008). Although these responses may appear to be overwhelmingly negative, research suggests that they are fairly generic in chronic illness (Cohen et al 1984, Rabins et al 1990, Keady and Nolan 1994, Lewis 1998, Halford et al 2000, Kralik 2002, Kralik et al 2000, Vernooij-Dassen et al 2006).

Furthermore, Bahro et al (1995) and Bender and Cheston (1997) both propose that apparently negative reactions from people with dementia such as

withdrawal, apathy and living in the past may actually play an adaptive role in overall coping. Certainly, it is reasonable to assume that these reactions occur for a reason. In one study that focused on couples facing dementia, Vernooij-Dassen et al (2006) proposed that the emotions associated with a diagnosis of dementia were often caused by the belief that they could no longer live by their norms. Other research also supports the idea that receiving a diagnosis of a chronic illness threatens one's sense of normality (Robinson 1993, Kralik 2002) with the presence of dementia meaning that life can become unstable (Clarke et al 2010). This study also supports this idea, with a number of couples reporting initial worries over their lives changing irrevocably.

However, couples in this study often reported that whilst they experienced these emotions intensely at the time of diagnosis, the intensity diminished somewhat over time. Evidence of this phenomenon is supported by the literature (Rabins et al 1990, Lewis 1998, Halford et al 2000, Kralik et al 2000) and the purpose of these heightened emotions may be to help overcome the shock that was so often associated with the diagnosis. Furthermore, models that chart the experience of chronic illness over time also support the idea that individuals experience a period of reaction in response to diagnosis before entering a period of adjustment (Cohen et al 1984, Keady and Nolan 1994, Nolan et al 1996a, Bender and Cheston 1997, Kralik 2002, Perry 2002, Clare 2003, Harman and Clare, 2006).

Therefore, this study provides further evidence for the existence of these two phases of adjustment. Couples in this study overwhelmingly seemed to develop certain thought processes which allowed them to access the adjustment period. That is they reported a desire to get on with their lives. The desire to "make the best of a very bad situation" was also reported by Todres and Galvin (2006 p.56). In this thesis this was represented in essence a desire to regain the sense of normality that had been threatened by the diagnosis. Indeed, as a result of the importance couples credited to maintaining a sense of normality, Chapter 7 devoted much time to discussing the various ways in which couples attempted to achieve this.

8.3.1.1 Changing identity

In this adjustment period, couples reported awareness and understanding of tangible changes such as those to memory, behaviour and ability to engage in social situations. Some couples demonstrated shared awareness by both describing these changes and offering similar anecdotes to illustrate them, whereas some couples approached these changes from different perspectives. For example, there were often subtle differences in the ways in which people with dementia and carers experienced these changes. For instance, whilst couples shared awareness that behavioural changes were likely due to dementia, carers found it much more difficult to assimilate behavioural changes than other dementia related changes i.e. memory loss. Indeed, carers often reported feeling that the person they married had essentially changed due to loss of confidence, increasing irritability and/or egocentricity. This supports previous research which also proposes that behavioural changes create the most difficulties for carers (Coen et al 1997, de Vugt 2003, Searson et al 2008, Zarit and Edwards 2008). Certainly for carers in this study, behavioural changes related to egocentricity were particularly awkward because they felt that they were working very hard for their spouse and did not feel that they received recognition for their efforts. Furthermore, although it has been reported that carers' lack of understanding can mean that they react in unhelpful ways (Quinn et al 2009), this was not always the case in this study. Most carers in fact demonstrated a very good understanding of the causes of such behavioural changes, but this did not change how they felt about it. Perhaps this is again an example of an apparently negative response that may actually be adaptive. For example, accepting that their spouse was not the person they used to be may allow carers to preserve good memories of their spouse (Lewis 1998, Baikie 2002). Therefore, previous research helps to explain the responses of carers in this study with regards to behavioural changes in their spouse.

However, historically there has been very little research into people with dementia's perceptions of this. This study has now illustrated that conversely, people with dementia did not tend to associate behavioural changes with a

change to them per se, and more often explained these changes in context of dementia. Thus, by being aware that these changes were part of the illness, people with dementia were able to compartmentalise them as 'due to dementia' therefore minimising the threat to their identity overall. Harman and Clare (2006) proposed a conflict for people with dementia between acknowledging the diagnosis and maintaining a sense of identity. However, the results of this study actually support the view that acknowledging the diagnosis is crucial to maintaining identity. This is because acknowledging the diagnosis encourages overall understanding which means that changes are more likely to be viewed in the context of the disease instead of attributed to the person with dementia. Therefore, where carers had some difficulty compartmentalising behavioural changes, people with dementia seemed better equipped to do so.

That is not to say that people with dementia were not susceptible to threats to their identity. In particular, people with dementia lamented no longer being able to take part in certain activities, such as writing, that had once formed an important component of their overall sense of identity. However, this apparent cloud may have a silver lining because it supports recent research which suggests that the central values and social cognition of people with mild to moderate dementia remain stable despite the presence of dementia (Westius et al 2009, Clarke et al 2010, Sabat and Gladstone 2010). Therefore, the reason that some changes proved more of a threat to people with dementia's sense of identity may be because these changes threatened their central values, the sense of which endures despite dementia. Therefore, it is possible that the person with dementia needs to take a longer journey with these changes in order to assimilate them without compromising the essence of their social being. These findings underscore the importance of acknowledging individuality in responses to dementia (Zarit et al 1998, Keady et al 2007, Westius et al 2009, Clarke et al 2010). This paragraph has highlighted the importance of upholding a person with dementia's sense of identity, and this was something that both people with dementia and carers in this study attempted instinctively. The potential for dementia to affect sense of identity was also identified by Clarke (1999) who suggested that a loss of self identity constituted a threat to the efficacy of normalisation. The ways in which couples

attempted to maintain a sense of identity were again linked to efforts to maintain normality. This will be discussed further in the coping section of this discussion.

8.3.1.2 Changing relationship

Furthermore, couples also reported on the impact of dementia on their relationship. Research would suggest that this is inevitable since the presence of a chronic illness means that roles are altered (Blanchard et al 1997, Schwartz and Ehde 2000, Sormanti and Kayser 2000, Vernooij-Dassen et al 2006) and boundaries can become blurred (Patterson and Garwick 1994). In dementia specifically, some research has suggested that close relationships become unbalanced as a result (de Vugt 2003). Certainly there was evidence from this study that couples experienced changes in roles. Within couples, partners demonstrated awareness of the fact that the person with dementia was now less able to contribute to chores and that this created more responsibility for the carer. Some research predicts that this change in balance of contributions could mean that the sense of reciprocity in the relationship is threatened (Walster et al 1978b, Neufeld and Harrison 1998, Quinn et al 2009). Furthermore, Clarke (1999) found that perceived reciprocity within the relationship can affect the efficacy of normalisation.

Certainly, the changes in roles and responsibilities did threaten the sense of normality particularly for carers who often described feeling trapped by their situation. In most cases this was due to the increased responsibilities they carried and because they missed having time to themselves, which is supported by the literature (Ohman and Soderberg 2004, Thommessen et al 2002, O'Shuaghnessy, Lee and Lintern 2010). This was difficult for carers because they realised that it was not their spouses' fault, so they did not know where to direct these feelings. This was compounded by carers' expectation that they 'should' be able to cope with their caring role, something which in the literature has been linked to societal pressure to be a good carer (Orbell 1996).

The evidence from this study is that feelings of reciprocity were affected by the ways in which carers reacted to dementia, and how these reactions were received by their spouses. For example, in two couples where the carer acted protectively in response to dementia, the person with dementia either felt comforted by this, or uncomfortable at the thought of being the protected as opposed to the protector. Therefore, arguably, the individual who was uncomfortable with the reaction of his wife may have experienced lower reciprocity because he was not content with the level of contributions he was able to make. Thus, two similar reactions from carers created two quite different reactions from their spouses. This finding again emphasises the importance of taking an individualised approach to understanding the lived experience of dementia for couples, by considering the historical make-up of the relationship, and acknowledging that the same stressors can be experienced differently by different people (Baider et al 1996, Orbell 1996, Blanchard et al 1997, Zarit et al 1998).

However, it was not only *changes* to the carers' behaviours that were problematic for people with dementia. In one example where a carer continued to put out her husband's clothes as she had always done, this seemingly benign action actually began to distress the person with dementia particularly as he was noticing several other aspects of their day to day life which now required his wife's input. This issue was resolved by the couple discussing it and the carer agreeing to stop doing this task for her husband. However, this did have implications for the carer who became aware of all of her actions towards her husband for fear of causing further offence. This supports the notion that the increased responsibilities experienced by carers did impact them in both practical and emotional ways. However, on the whole, despite these pressures, carers in this study took their increased responsibilities very seriously and were eager to do the absolute best for their partner. Similarly, people with dementia, aware of the burdens on their spouse, also made attempts to do what they could in order to help their carers with the responsibilities.

8.3.1.3 Changing communication

Communication within couples was central to the success of achieving a sense of normality. Marwit et al (2005) found that carers demonstrated a better awareness of how dementia impacted communication within their marriage than people with dementia, who they argued focused on the more concrete aspects of communication. Marwit et al developed stages of communication for couples facing dementia which represent the chronological stages associated with awareness of dementia. For example, suspicions about dementia are followed by mutual pretence, which then moves to safe topics of discussion, then touching on difficult topics, before open communication sees more candid discussion of issues. Thus, the authors argued that communication was strongly linked to awareness. For example, when couples limit conversation to safe issues, it is likely that the carer knows more than they chose to disclose so as not to upset their spouse, whilst the person with dementia may have a limited awareness that some issues are purposely being avoided. With regards to developing a shared awareness within couples, Hellstrom et al (2005) found this to be developed through shared understanding about dementia. Namely, awareness of memory difficulties and associated problems, awareness about how these problems may develop in the future, and also awareness of the impact of dementia on their spouse. The authors termed this 'Nurturative Relational Context' in appreciation of the relational aspect of communication within couples in dementia.

As illustrated in the beginning of this chapter, couples in this study did demonstrate awareness of these three features, which Hellstrom et al propose are the building blocks for developing a shared awareness of dementia. However, the findings of this study support a more individualised response to dementia. For example, even where both partners did demonstrate awareness of the three features individually, this did not always mean that they went on to develop shared awareness. As outlined above, this mostly reflected their natural way of communicating with each other. Furthermore, whilst Marwit et al argued that the final 'open' level of communication was the most adaptive, Hellstrom et al (2005) suggested that awareness in dementia cannot feasibly

be 'open' but rather 'uncertain open' which means that whilst the diagnosis is acknowledged, couples try not to focus on the negative aspects of it and instead try to adopt a positive approach to it.

The results from this study support this view generically. For example, carers demonstrated awareness of the potential impact of dementia related challenges on communication and as such, they often reported making a special effort with communication such as trying to remain calm while answering the same question over and over, and learning to talk to their spouse without coming across as being patronising. Carers often did this subtly in order to preserve their loved ones' dignity, thus downplaying the negative aspects of dementia. Furthermore, carers were careful not to blame all communication difficulties on dementia, and made efforts to disentangle what was memory loss or a lack of concentration as opposed to what was hearing or the result of too many distractions, thus adopting a more positive approach. Again, couples were motivated by the sense that they wanted to get on with their lives and gain a sense of control and normality over the situation. Therefore, it is certainly feasible that couples attempted to minimise the impact of the change in roles and reciprocity within the relationship in order to minimise the impact of dementia overall, thus supporting the idea of 'uncertain open' communication (Hellstrom et al 2005). However, this study has demonstrated that these inherent ways of coping, termed 'lessen the load', sometimes prevented couples from discussing their awareness of dementia, which therefore sometimes prevented them from developing a shared awareness.

Hellstrom et al (2005) proposed that couples who deal with dementia independently and who do not developed a shared awareness of dementia are at a higher risk of drifting apart. The results of this study, however, do not necessarily support that. In fact, couples who coped independently were largely just carrying on their normal coping patterns. It was the couples who were used to working together, and who were now trying to cope independently who were finding this more difficult. Therefore, it is important to be aware of the historical nuances within relationships before making

assumptions about the efficacy of the ways in which couples cope. Thus, it is clear that researchers and clinicians should seek to understand both how partners view their relationships, and how they view the role of caregiving within that relationship in order to respect the characteristics of individual couples (Carpenter and Mak 2007).

Thus, in addition to previous research, this study illustrated vast differences among couples as to what constituted an *acceptable* level of communication and awareness. Again, this was strongly linked to how each couple had communicated historically, with some couples reporting frequent discussion about all kinds of issues, to others who reported that they had very rarely discussed any awkward issues. Therefore, it may be that in order to ascertain how individual couples communicate effectively one needs to recognise that couples have different expectations with regards to communication.

Therefore, although some previous research proposes that awareness and communication within dementia can be thought of as discrete phases through which couples progress, the result of this study suggest that how couples respond communicatively to dementia both determines the development of shared awareness but that the ways in which they respond are also determined by their own awareness and their historical ways of communicating both as individuals and as a couple. Within that, couples' responses to dementia are better represented by a continuum of communication which transcends shared open discussion through to closed communication in recognition of the fact that couples enter their experience of dementia with different pre-morbid expectations of communication with their partner.

Indeed, despite apparently unreciprocal relationships, research supports the idea that relationships in chronic illness do survive due to love and/or the obligation to keep the relationship alive as well as an understanding that the carer is happy to provide care for their loved one in return for the many years of care previously provided by the person with the chronic illness (Lewis 1998, Sandberg and Eriksson 2007).

8.3.2 What coping strategies are employed by people with mild dementia and their spouses?

This part of the discussion will focus on how couples attempted to cope with dementia. It will first address the roles played by different types of coping strategy that were reported with regards to people with dementia and carers as individuals, before addressing how the use of these strategies may affect coping within couples.

Research into coping in general has highlighted two types of coping strategy: problem-focused and emotion-focused. Problem-focused strategies are those which allow changes to be made to the environment or person that was causing distress, and emotion-focused strategies are those that regulate stressful emotions (Folkman et al 1986). In the field of dementia, it was thought that problem-focused coping was more adaptive than emotion-focused (Quayhagen and Quayhagen 1988, McKee et al 1997, Clare 2002), but other research suggests that emotion-focused strategies can be used successfully in chronic illness (Coyne et al 1981, Berg-Weger et al 2001, de Boer, et al 2007, Stanton et al 2007). Moreover, this may be because emotion-focused strategies are often used in response to harm or loss (Aldwin 1994) and situations that seem 'unchangeable' (Folkman et al 1986), both of which arguably apply to dementia.

In the field of dementia, research has largely focused on the carer's use of coping strategies, and to a lesser extent the person with dementia. In both there is evidence of the use of problem and emotion focused coping strategies (Ingebretsen and Solem 2002, Matson 1994, Bahro et al 1995, Keady and Nolan 1995a, Almberg et al 1997, Bender and Cheston 1997, Szabo and Strang 1999, Woods 2001, Clare 2002, Charlesworth et al 2007, Ott et al 2007, de Boer et al 2007, Stanton et al 2007). However, it is not clear from the literature how coping strategies are developed within couples i.e. what roles each person plays in the development and maintenance of strategies.

As detailed at the beginning of the discussion, couples within this study described their lived experience of dementia as a process. This part of the discussion will focus on the ways in which couples attempted to cope with dementia once they had entered the period of adjustment in which the emotions associated with diagnosis had begun to diminish in intensity. This began with couples overwhelmingly describing that they wanted to get on with their lives, again to regain some control and a sense of normality. The idea that people with dementia be permitted to live as normally as possible was also supported by Page, Keady and Clarke (2007) who proposed it as one of the primary aims of health and social care services.

As discussed earlier, couples demonstrated a good awareness and understanding regarding dementia, and following diagnosis, some couples attempted to put together explanations as to why this had happened to them. This process seemed to be more important for people with dementia, with all of them describing efforts to understand why it had happened to them. Explanations were often made that fit with their individual history and view of the world. For example, one lady with dementia felt that because in her job she had always written everything down that she had got into the habit of not remembering things, and similarly one lady with dementia put her dementia down to having nothing to occupy her mind when she retired. Whilst these examples, and others, were probably not to blame for the onset of dementia, it nonetheless seemed important that people with dementia developed a reason for their dementia which made sense to them (Matson 1994). Furthermore, this process of trying to explain why this had happened arguably involves the use of both a problem-focused strategy such as 'confronting the problem' as well as an emotion-focused strategy such as 'acceptance' (Almberg et al, 1997).

Therefore, a desire to understand why dementia had happened to them was an important starting point for the people with dementia in this study. In support, Wuest et al (1994) also found that carers attempted to explain the changes. However, in this study, people with dementia making attempts to explain had a mixed reception from carers with some actively discouraging rumination over why this had happened, whilst others were happy to discuss

the possibilities with their spouse. Again, this seemed to reflect historical communication styles within each couple, where some couples shared narratives and some did not. This was further illustrated in how couples referred to dementia, with some couples using the same terminology and others using different terminology. In both instances, this did not necessarily indicate better or worse coping styles, but rather reflected the ways in which couples were used to communicating.

A need to explain the changes was also found by Clare (2003) who presented similar evidence of a tendency to attribute changes associated with dementia to normal parts of everyday life. She argued that this enabled people with dementia to normalise dementia, but also suggested that normalising activities promoted maintenance rather than real adjustment. Adjusting strategies identified by Clare were representative of a clearer understanding of dementia, for example by acknowledging the role of changes in the brain as well as the fact that dementia is more than just the ageing process. Therefore, self maintaining strategies protect sense of self through normalising the situation, and self adjusting strategies confront changes and adapt sense of self. Evidence for both types of strategy was found in this study. Moreover, there was evidence that people with dementia used both strategies concurrently which supports the idea that couples used their understanding of why this had happened and what it meant for them in order to face up to challenges and adjust accordingly in order to maintain a sense of normality. For example, Couple 11 continued to sing in a choir (self maintaining), although they were both aware that PWD 11's ability to take part independently had deteriorated. Therefore, in order to allow PWD 11 to adapt her sense of identity but still enable her to take part in something that was important to her (self adjusting), they devised subtle ways for Carer 11 to prompt and support her. Therefore, this study found that normalisation and adjustment, instead of being two separate entities, are actually intrinsically linked.

Therefore, instead of one type of strategy being more efficacious than another, the results of this study have shown that coping strategies play their own role in the overall coping experience. This supports existing literature in that it

acknowledges that problem-focused may be most effective in dealing with situations that can be changes and emotion-focused strategies are better for situations that cannot be changed (Folkman et al 1986). Arguably, couples cannot change the fact that one partner has dementia but they can change certain aspects of their lives, both practically and emotionally, in order to make the best of the situation. The results of this study suggest that couples' experienced a motivation towards maintaining a sense of normality in their lives. Within this, this thesis has shown considerable support for the successful use of emotion-focused strategies, which is in keeping with some research which argues that emotion-focused strategies can be effectively utilised in chronic illness (Coyne et al 1981, Berg-Weger et al 2001, Stanton et al 2007). Moreover, by interviewing both the person with dementia and their spouse, this thesis has furthered understanding into how emotion and problem focused coping strategies are developed and used within couples.

The next part of the discussion will consider the four main ways through which maintaining a sense of normality was achieved. The first is an example of an emotion-focused strategy which saw couples focusing on the *development of positive cognitions*. The second way charts the use of more problem-focused strategies which focused on *keeping active*. The third way details the efforts made by partners to *lessen the load* on each other. This was another emotion-focused strategy that was adopted by couples and formed an important part of their overall coping. Lastly, another emotion-focused strategy saw couples engage in *direct discussion and support*.

8.3.2.1 Development of positive cognitions

Couples were very good at developing shared positive cognitions in response to dementia. Reaching acceptance was described by couples as the outcome following learning about dementia as a disease and what it meant for them. Here, it could be argued that carers' active discouragement of discussion about why it had happened could actually be a positive encouragement i.e. that awareness that there was nothing they could do about it, could be turned

into a positive by encouraging them to get on with their lives. Therefore, again apparently negative behaviours may actually be conducive to overall coping.

Positive thinking within couples was achieved by on the one hand seeking information about dementia, but also, and importantly, by focusing on the here and now (Lyons et al 1995), and pushing thoughts about the future to one side. Of course, couples were aware of what the future may hold, but also that the future was unpredictable and therefore that there was little point in worrying about something that may or may not happen. This provides an example of the use of further emotion-focused strategies such as 'reframing the situation' and 'discovery of inner strength' (Berg-Weger et al 2001). Therefore, this study provides further evidence that the use of emotion-focused coping strategies fosters the development of positive cognitions in dementia (Berg-Weger et al 2001, Ott et al 2007).

Couples also demonstrated a sense of optimism which was usually linked to downward comparisons which reminded them that there were people worse off than them, and that other people forgot things too. This also encouraged their sense of normality because it enabled couples to appreciate the things that they did still have. This was further enhanced, particularly for people with dementia by recognising their achievements over their lifetime, because it helped to uphold their sense of identity. In support, research suggests that couples undergo a life evaluation and make positive reflections in response to dementia (Daniels et al 2007), and therefore, this study provides more evidence for the importance of this in order to help couples maintain identity and develop positive cognitions, both of which help overall feelings of normality.

Several couples also referred to the acetylcholinesterase inhibitor medications and their effect on the person with dementia. In keeping with research by the Alzheimer's Society (2004) in which 73% of carers felt that the medication had worked, couples in this study were overwhelmingly keen to talk about their medication and also report its positive effects. A positive association was also found by Cummings et al (2004) who reported a reduction in caregiver stress

in those carers whose loved ones received active therapy. In this study, couples often reported that they had noticed a halt, or even improvement in their cognition, since the person with dementia had been taking their medication. This finding is supported albeit to a lesser extent by Hutchings et al (2010) who reported that some of the treatment users in their sample said that they had noticed a difference since beginning their medication. Carers in Hutchings' study, on the other hand, reported little impact on their daily lives although they did see the benefit in feeling that something was being done.

Of course, research into the impact of these medications on people with dementia is in its infancy (Hutchings et al 2010), with research into the impact on couples even more so. Indeed, whilst Hutchings et al's study included both people with dementia and carers, it is not clear whether they were from the same couples/families, and no attempts were made to understand the impact from a dyadic perspective. Therefore, this study is useful in explaining the usefulness of acetylcholinesterase inhibitors for couples not just as a pharmacological contribution, but also in three other unique ways. First, as outlined above, the use of medication gave couples hope which was conducive in the development of positive cognitions. For example, this study saw exclamations about medication such as "I came alive again", which undoubtedly helped couples to think more positively about their situation. Furthermore, this perceived halt gave couples the chance to regain parts of their lives which they thought were lost. Lastly, couples were very comfortable using the medication as a platform through which to discuss specific impairments and perceived improvements as well as how they were managing generally. This may reflect the perhaps practised conversation which couples take part in at the Memory Clinic, but nonetheless, it allowed couples to talk about all kinds of issues. Therefore, this study provides improved understanding of the perspectives of people with dementia regarding their medication, which Hutchings et al (2010) argue is a somewhat 'ignored perspective' (p.412) as well as couples as a whole.

Contentment was reported by some couples who focused on the positive aspects of their lives. This was associated with couples feeling satisfied that

they were living a full life, and having therefore reached their aim of getting on with their lives. However, not all couples who reported living a full life also reported feeling contented. Therefore, it is likely that there is more to contentment than following a series of discrete steps such as formulating understanding of the disease and its meaning. Indeed, perhaps this reflects different personalities whereby some people may be more able to accept that they had moved into a new stage of their life than others. For example, one man with dementia who described his life to date as very exciting and interesting, did not want to accept that this time of his life should be any less exciting and interesting. Indeed, there is a fine line between developing a fighting spirit through which one can achieve realistic goals, and developing expectations that are unlikely to be met. Perhaps this distinction explains the difference between whether couples felt contented or not. In support, DeLongis and Holtzman (2005) reported that coping is influenced by nature of the stressful event as well as social context in which it occurred and personalities of those involved.

This section has outlined the ways in which couples developed positive cognitions. This has again reiterated the importance of recognising individuality in the development of positive cognitions. Therefore, it is important to identify these strategies not least because research attests that maintaining a sense of normality in chronic illness is only achieved through constant effort (Kralik 2002). Therefore, this thesis is useful because it has improved understanding of the ways in which positive cognitions and sense of normality are fostered in couples. The literature at large supports the importance of this input, with 'achieving a balance between hope and despair' (Clare 2002), 'acceptance' (Cohen et al 1984, Kitwood 1997, Clare 2002), 'maximising' (Keady and Nolan 1995), and 'achieving normalisation' (Robinson 1993, Clarke 1999, Kralik 2002) – all of which ultimately involve the people involved getting to a point where they feel they own the illness instead of it owning them – being reported as key to coping with dementia. In this study, this process has been referred to in terms of normality since this seemed to be at the core of most coping efforts made by the couples.

8.3.2.2 Keeping active

Keeping active was a huge part of the couples' coping efforts, not least because it featured across their everyday lives. Herein lays the reason for its importance and the reason that keeping active strategies often became the focus of attention for couples facing dementia whose goal was to get on with their lives. Therefore, keeping active strategies were motivated by the need to maintain a sense of normality, which was often achieved by maintaining the involvement of the person with dementia.

Couples in this study reported the use of routine, which is also supported by the literature (Wuest et al 1994, Sandberg and Eriksson 2007, Clarke et al 2010) as an important part of overall coping because it allows carers to gain a sense of control. In this study, couples used routine as an orientation aid which also provided a sense of comfort for the person with dementia who knew what to expect on a day to day basis. This allowed for certain activities and outings to be practised and therefore brought with it a sense of control for couples. This enabled couples to maximise their sense of independence, which was important for people with dementia certainly, but also to some carers who reported feeling rather trapped by the situation. Furthermore, couples reported that taking part in a 'normal' activity such as going for a walk was a pleasurable activity since there was no pressure to reveal the dementia. Therefore, partaking in 'normal' activities was one way in which couples kept busy.

However, couples put considerably more time and effort into ensuring the *meaningful* involvement of the person with dementia. This meant that the person with dementia was able to continue, at least to some degree, with activities that meant something to them personally and therefore contributed to their self-identity. This included activities that represented a fighting spirit against dementia such as mental activity which aimed to keep their brains working, and physical activity to keep their bodies fit and active. Where this was achieved through activities that were important to them, such as keeping fit by gardening, this had a twofold positive impact of keeping them physically fit and also contributing to their feelings of self-identity. The importance of

meaningful involvement for the person with dementia is strongly upheld in the literature (Keady 1999, Perry 2002, Hellstrom et al 2005 and 2007).

Furthermore, shared activities that focused on affection and companionship such as spending time with family, being appreciated, being outside and indeed just 'being' have been reported as important components of the coping experience (Todres and Galvin 2006, Searson et al 2008).

This study has revealed further evidence about how meaningful involvement is upheld in couples facing dementia. Certainly, it was clear that people with dementia knew what they would like to do. However, more often than not it was the carer whose input made these wishes a reality. This was achieved in subtle ways such as ensuring that they always asked their spouses' opinion, as well as encouraging the person with dementia to try things for themselves and keep up with activities that would uphold their sense of identity. In many cases, couples reported being together much more frequently (sometimes always) and this too seemed to help people with dementia who reported feeling comforted by their spouses' presence. Often, couples reported ways in which they subtly dealt with any mishaps, particularly in public, and this meant that people with dementia were more confident to continue with meaningful activities because they knew that their spouse would be there to support them. This sometimes required quite intense involvement on behalf of the carer in order to successfully maintain the involvement of their loved one in meaningful activities. This success may in fact be due to differing levels of problem-focused coping strategies used by each member of a couple, which Pakenham (1998) suggested was conducive to the individual and dyadic adjustment of couples where one partner had multiple sclerosis.

However, this heightened level of involvement required of carers sometimes meant that they felt trapped or exhausted, and unable to keep up with activities that enhanced *their* self identity. This is supported by Clarke (1999) who found that a loss of self-identity for carers threatened their overall sense of normalisation. More recently, Hayes et al (2010) found that wife carers were reluctant to discuss concerns about changes they had observed in their spouse, in part because they sought to uphold their own sense of self. The

authors found that husband carers were better able to normalise, because the husband's role was less threatened by their wife having dementia, than the wife's role was if their husband had dementia.

This study has provided further insight into how normalisation is developed within couples, namely that carers' primary motivation was to maintain a sense of normality for them and their spouse as a couple, rather than focusing on their own sense of normality. Therefore this may explain the efforts put in by carers despite the detriment to themselves in order to uphold the person with dementia's meaningful involvement. Indeed, Clarke (1999) supports this idea, saying that whilst these types of strategy are successful in upholding a sense of normalisation overall, they also have costs to the relationship.

However, the efforts of carers in this area were well rewarded since not being able to take part in an important activity was most likely to make people with dementia report that they did not feel like themselves. Therefore, whilst recognising achievements and the development of positive cognitions were important, couples reported considerable benefit from being able to carry on with aspects of their lives that were meaningful. Indeed, people with dementia did not necessarily require the same level of input as previously, it was involvement at any level which was the important factor. Indeed, carers in this study highlighted that were perfectly placed to understanding what would constitute meaningful for their loved one, and to interpret their meanings accordingly (Perry 2002). This also supports Hellstrom et al's (2007) findings which suggest that couples in the mild stages of dementia sustain feelings of couplehood through talking things through, being affectionate and making the best of things whilst ensuring that involvement of the person with dementia is maintained. The benefit of both spouses keeping active may be explained by the fact that the challenges associated with dementia are new to couples, and hence may require the active engagement of the carer in order to be successfully managed. Conversely, De Ridder et al (2005) found that people with asthma and diabetes, who were well practiced in their illness-related challenges, did not overly benefit from their carers' active engagement. This

may explain further why the carers' input is so important in coping with dementia for couples.

8.3.2.3 Lessen the load

Indeed, the couples in this study demonstrated that their understanding of the individual responses of their partners was paramount to the ways in which they then attempted to cope. This part of the discussion will consider the ways in which couples attempted to lessen the load on each other. This is not something which has been overtly reflected upon in the literature, perhaps due to the methodological limitations associated with only including either the person with dementia or the carer in research. However, Clarke et al (2010) quoted one lady with dementia who specifically referred to 'lift the load', and in this study, attempts to lessen the load on their partner were a key part of couples' overall coping efforts. Such activities have also been reported with regards to carers of spouses with asthma and diabetes, where it was termed 'protective buffering' (de Ridder et al 2005). Furthermore, evidence that carers of people with dementia also work independently from their partner in order to reduce stress on their loved one was recently reported by O'Shaughnessy et al (2010).

The motivation for lessening the load on their partner was borne out through an understanding of dementia and an appreciation of the impact of dementia on their spouse. In most cases, people with dementia and carers acted in order to protect their spouse from any further upset or perceived burden. Here both people with dementia and carers reported taking a passive approach whereby they went along with their spouse even if they did not agree with them. This use of what may be considered passivity (Matson 1994) is a further example of how emotion-focused strategies were used adaptively within couples, whilst 'compromising with others' was also reported by DeLongis and O'Brien (1990) as part of their relationship-focused coping. These studies, coupled with the evidence from this study, support the importance of emotional support in couples facing dementia. This was also identified by Hellstrom et al's (2005) Nurturative Relational Context which outlined the ways in which

couples seek to re-establish their relationship according to new challenges associated with dementia.

This thesis has identified further ways in which couples attempt to do this through the inclusion of both the person with dementia and their spouse, and the use of separate interviews, because this enabled the consideration of how the same issues were thought about and managed by each partner. For example, people with dementia reported making efforts to find things out for themselves instead of asking their spouse. This was motivated by the understanding that dementia was sometimes difficult to manage and therefore that they did not want to burden them any more than they had to. This referred to practical tasks, but also to the emotional impact of dementia with people with dementia demonstrating a good understanding of the frustrations experienced by their carers. Largely, however, the efforts made by people with dementia to lessen the load went unnoticed by the carers of this study.

Carers' attempts to lessen the load were also largely unnoticed by their partners, and centred on providing a stable and comforting presence and on communication. As demonstrated in the 'keeping active' section above, carers provided much of the motivation and encouragement which meant that people with dementia maintained meaningful involvement in their day to day life. However, the ways in which the motivation and encouragement were given depended somewhat on how carers felt their spouse would respond if they felt they were deteriorating. For example, one carer believed that her husband's diagnosis had 'destroyed him as a man' and for that reason was hesitant to confirm any deterioration. This was also found by Hayes et al (2010) who reported on the differences between husband carers and wife carers in their responses to the symptoms of dementia. These authors found that a reluctance to discuss concerns amid fears of confirming the diagnosis was found predominantly in wife carers. However, this may be conducive to coping with de Ridder et al (2005) reporting that males with asthma or diabetes actually benefited from their wives' reluctance to share their concerns with them or as they termed it 'protective buffering'. However, when husbands were reluctant to share concerns, this had the opposite effect on wives with asthma

or diabetes who reported worse physical health. The authors also reported that patients' well-being seemed to determine whether they would benefit or not from protective buffering. However, their study focused on the impact of carers' coping efforts on the person with the illness, and therefore did not examine what attempts, if any, were made by the people with the illness to protectively buffer their carers.

In this thesis, there was evidence that both wife and husband carers, and people with dementia, experienced some trepidation about discussing concerns. For example, some carers had worked so hard to create a sense of normality in their lives, that they did not dare discuss any issues with their spouse for fear of contradicting the very normality they were trying to uphold. In these cases, carers reported using a more subtle approach to motivate their spouse. Like people with dementia, carers also reported that they avoided talking about awkward issues with their spouse so they could avoid upsetting them. However, this had implications for both partners because they lost their confidante, particularly as they also reported feeling uncomfortable discussing these issues with other people.

However, couples were in a unique position to be able to do this successfully since their knowledge of how their partner would react was used as power in how they then decided to proceed. Moreover, couples could contextualise their partners' responses in terms of how they had responded to difficult times throughout their lives and therefore, this information helped them to respond to their partners in the most appropriate ways. This knowledge was utilised by both people with dementia and carers. In most cases, couples' first instinct was to carry on as they always had, whereby some couples discussed issues and some did not. Again, continuing in the same ways enhanced the sense of normality about the situation, which was a key goal for couples.

In the minimal literature on communication in couples facing dementia, Marwit et al (2005) proposed that couples move through different types of communication: essentially from closed to open. However, along the journey there are points at which Marwit et al found that there were discrepancies

within couples about how open they considered their communication to be. In support, there was evidence in this study of discrepancies within couples where one partner felt they communicated openly whilst the other reported being reluctant to discuss some issues. However, the results of this study suggest that such discrepancies were sometimes carefully engineered by either people with dementia or carers, or both, in order to make the best of the situation. Remembering that couples were keen to get on with their lives, and together developed positive cognitions to support that aim, couples then focused on achieving that aim on a day to day level. Therefore, although Marwit et al (2005) proposed that open communication was the most adaptive stage of the model, the findings of this study support the view that less open communication styles also have their benefits, and are more appropriate than open communication for certain couples at certain points of the disease process. For example, some people with dementia reported appreciating their spouses' attempts to take a sensitive approach to communication by being patient and kind, and this level of reassurance was enough for them to feel supported without formally discussing why they might need reassuring. Therefore, whilst a sensitive approach was conducive for coping in couples, the benefit increased when partners recognised the efforts their spouse was making. Thus, it may be useful for couples if they were to be more aware of the attempts their spouse made to lessen the load.

8.3.2.4 Direct discussion and support

As with the other areas of coping, the extent to which direct discussion was accessed as a strategy for coping was linked to premorbid patterns of communication within the couples. Therefore, some couples did not really discuss issues whereas others were used to discussing lots of different issues. This finding is supported by Roberto et al (1998) who proposed that pre-existing communication patterns are exaggerated by dementia. However, not all hindrances to discussion in this study were linked to premorbid communication practices. For example, some people with dementia felt that they had lost confidence in their ability to converse, and some reported a barrier to conversation with their spouse. Furthermore, the section above on

lessen the load illustrated some instances where partners purposely avoided direct discussion, and for valid reasons which held their spouses' best interests at heart. Moreover, the literature suggests that meaningful communication within close relationships in dementia and other chronic illnesses can be difficult to attain (Keady and Nolan 1995b, Rees et al 1998, Pistrang et al 1999, Hayes et al 2010).

However, effective communication although not always easily engaged in, has been linked positively in the literature to coping (Vess et al 1985, Searson et al 2008). Happily, this study found many examples of how direct discussion could really benefit both partners. For example, one person with dementia asked his wife to rephrase her speech and rather than tell him what they were going to do or eat, he requested that she ask him. Similarly, this is the same PWD who asked his wife to stop putting his clothes out for him. On both occasions, his wife would not have known she was causing offence had her husband not told her. As it was, this simple yet direct discussion meant that this issue was easily resolved. Furthermore, it left the person with dementia feeling validated and the carer pleased that she could avoid offending her husband. Being consulted on matters was something other people with dementia also brought up, although not all of them had discussed this with their spouses. Again, this was sometimes because people with dementia did not want to burden their spouses any more than was necessary (Hellstrom et al 2005).

Yet discussion, when done sensitively actually had further benefits with regards to emotional support in particular. When carers discussed an issue with their spouse, the impact was twofold. On the one hand, this encouraged the person with dementia to share their concerns, and additionally by the carer admitting their concerns, this enabled the person with dementia to provide emotional support. This was important for people with dementia as they were confident that this was something they could still offer. Furthermore, having the opportunity to offer emotional support reinforced their role as a husband or wife, which allowed them to focus on this part of the relationship rather than letting their relationship be defined simply as one of 'care-recipient/carer'.

This phenomenon is similar to one presented by Lewis (1998) called 'complimentary disabilities' in which Lewis acknowledged the importance of both partners feeling that they are supporting the other in one way or another. For example, the carer is supporting their spouse with dementia, whilst the person with dementia is supporting their spouse with diabetes or arthritis. This study, however, goes one step further and suggests that couples may not only support each other in concrete, practical ways but also by allowing their spouse to see that they each have vulnerabilities which require emotional support. Further support for emotional support was found by Sormanti and Kayser (2000), who interviewed women with breast cancer and found that although emotional support was considered by the women to be very important, it was the least readily offered type of support provided by their spouses. However, the authors did not ask the spouses whether they thought they were providing emotional support. Nonetheless, this does highlight the need for emotional support to be a two-way interaction in couples facing chronic illness. In dementia, in particular, the opportunity for people with dementia to offer emotional support was central because they felt able to do this despite their dementia. Emotional support in this study was generally provided in two ways with regards to direct communication. The first involved rather light-hearted ways of support such as joking with one another and bringing up issues casually on a day to day basis. The second involved more formal methods of communication particularly with regards to serious issues. The extent to which these methods were utilised again seemed to be linked to premorbid styles of communication. Moreover, both methods enhanced feelings of normality for couples because they were able to provide valuable emotional support to their spouse, which was in keeping with the ways in which they had supported each other throughout their lives. Therefore, perhaps couples' ability to share 'complimentary vulnerabilities' is important in the development of effective communication practices. This is supported by Keady and Nolan (2003) who found that couples who 'worked together' coped more successfully than those who worked alone, separately or apart.

Furthermore, carers continued to play a crucial role in direct discussion (as with the other areas of coping outlined in this chapter) because they used their

knowledge of their spouse to determine what type of communication method was most appropriate for that time/situation. Therefore, carers reported changing their method of communication depending on how they thought their spouse would respond at that time e.g. direct discussion, reassurance, change of subject.

However, couples reported most benefit from making discussion a part of everyday routine whereby both partners reported feeling content that they could discuss anything they wanted to. This is supported by Hellstrom et al (2007) who proposed that talking things through is a fundamental part of 'sustaining couplehood' for couples facing dementia. This study also identified that talking things through allows couples to inadvertently reassure partners that they are in this together (Keady and Nolan 2003). Couples in this study found this useful when they felt frustrated because it helped them to reiterate that they were frustrated with dementia rather than with the person with dementia.

8.3.2.5 Relationship continuum

Previous research presented across this thesis illustrates that couples in which one partner has dementia face unique challenges. The findings of this thesis also support this with couples identifying numerous difficulties and changes to themselves, their partner, their relationship and their lives generally as a result of dementia. However, it is reassuring that couples were both able to identify these challenges and were also able to devise strategies for coping with them.

The ways in which couples respond to dementia has been considered in the literature, and models have been developed which chart the ways in which couples develop a sense of shared awareness (Hellstrom et al 2005), communicate (Marwit et al 2005, Hellstrom et al 2007) and manage coping efforts as a couple or individually (Keady and Nolan 1994, Hellstrom et al 2005 and 2007).

This thesis has furthered understanding of the roles played by both people with dementia and their spouses in the development and maintenance of strategies based on the motivation to uphold a sense of normality in their lives. Specifically, it is identified the importance of communication within couples and how the nuances of historical communication patterns affect how couples continue to communicate which influences which coping strategies are adopted. Thus, the evidence from this thesis supports the view that couples' responses to dementia (i.e their experience of the impact of dementia and their attempts to cope with it) should be thought of on a continuum which acknowledges that differences in communication and awareness will determine different expectations with regards to what kind of reactions are acceptable. Indeed, couples in this study who appeared to be 'working apart' as it may be termed by Keady and Nolan (1994) were in fact simply continuing to behave as they had done throughout their lives, and at the point of interview, this was working successfully for them.

Within this, both maintaining and adjusting strategies were used by couples, and whereas Clare (2003) proposed that adjusting strategies promoted real adjustment as opposed to maintaining strategies which promoted maintenance, there was evidence for the successful concurrent use of both strategies in this thesis. Furthermore, it could be argued that maintenance of the situation was actually the focus for most couples i.e. that the person with dementia was able to maintain involvement in activities that were important to them, and thus uphold their sense of normality. However, maintenance of the situation was often achieved through the use of both types of strategy (see example on p.261) and therefore rather than adjusting strategies being more helpful than maintaining strategies, the concurrent use of these strategies seemed to be more important for achieving a sense of normality. Of course, the extent to which individual strategies were utilised rather depended on each individual couple and the ways in which they were used to responding to stressful situations.

This thesis proposes that a sense of normality is very important for couples who face dementia. It identified four key ways in which this was achieved and

the strategies used by couples within this were all determined by the historical nature of their relationship. With regards to 'positive cognitions', there was evidence that all couples had developed positive ways of thinking about their situation, but that this was achieved in different ways depending on how much the couple communicated about dementia. This thesis identified that all couples were willing to talk to each other about dementia in terms of the medication with regards to perceived impact of dementia, changes and hopes. This may reflect practised conversations at the Memory Clinic, but nonetheless it does provide a useful forum for discussion particularly for those couples who may not routinely discuss dementia.

Similarly, the ways in which couples 'kept active' were related to both which activities the couple enjoyed (both individually and together) as well as the level of participation both in terms of frequency and intensity. Thus, the idea of a continuum is useful here too, because it accepts that the idea of keeping active will mean different things to different couples. For example, maintaining the involvement of the person with dementia in meaningful activities was important to carers in this study, who often made great efforts to ensure that this was done. It is important for researchers (and practitioners) to realise that both members of a couple may be used to these roles (in that one partner may have predominantly acted as leader whilst the other partner took a less dominant role), or they may be a direct reversal. It is inevitable that this will affect how easily the transition is made for both parties. Moreover, individual characteristics around being cared for and acting in a carer way towards others will also affect this balance. Therefore, research should accept that couples begin their journey into dementia from different starting points and will therefore have different expectations of their experiences.

All couples demonstrated ways in which they attempted to lessen the load on each other. This was done either passively or actively and was a result of awareness about dementia and understanding about the perceived or potential input on their spouse. Furthermore, couples used their knowledge of their spouse in order to respond in the most appropriate and conducive ways with regards to dementia. For some couples, this encouraged them to continue a

minimal discussion about dementia since this was in keeping with how they addressed issues generally. Other couples attempted to talk to each other but with subtlety and dignity in order to protect one another's feelings. This section also demonstrated that apparent discrepancies in communication (for example, when one partner thought they were communicating openly with their spouse whilst the other spouse acknowledged that they held back) were actually carefully engineered in order to maximise their sense of normality. Therefore, although all couples did try to lessen the load on each other, the ways in which this was achieved differed again due to historical nuances of the relationship, hence supporting the idea of a continuum as opposed to discrete strategies.

Finally, some couples did partake in direct discussion of dementia, and the benefits of these discussions were considered in Chapter 7. Specifically, the discussion of difficult issues and thus sharing of complimentary vulnerabilities meant that both spouses were able to provide and receive emotional support. Again, the extent to which this was used in couples depended on their historical communication style which justifies the development of a continuum of response rather than models that focus on discrete responses.

8.4 Summary and contribution to knowledge

This chapter has illustrated how this thesis has addressed the research questions and overall aim and thus made a unique contribution to the literature. This thesis revealed that couples described their experiences of dementia as a process, and has outlined the ways in which couples experienced and then attempted to cope with challenges as they occurred. That the experience of dementia can be represented as a process is accepted in the literature, but this thesis has developed existing work by simultaneously exploring the lived experience of dementia for people with mild dementia *and* their spouses. Importantly, it has provided evidence to support the view that marital relationships endure despite the mild stages of dementia (Gladstone 1995, Gallagher-Thompson et al 2001).

The first research question explored how people with dementia and their spouses described the impact of mild dementia on their lives and relationship. Findings from this thesis provided support for the existence of a process that began with suspicions that something might be wrong, followed by the confirmation of the diagnosis. At that time, couples retrospectively reported experiencing heightened emotions from different ends of the spectrum, from shock and depression, to relief. The next stage of the process was to move into a period of adjustment. At this time, couples reported wanting to get on with their life, that was to regain a sense of control and normality. This is in-keeping with previous research into both people with dementia and carers as individuals as well as research into couples' experience of dementia.

Within the adjustment period, couples reported awareness of impacts across three key areas. The first was changing identity, in which couples described the changes caused by dementia and the potential and perceived impact on sense of identity. People with dementia were better able than their carers to compartmentalise behavioural changes as part of dementia. In fact, the findings in this area suggested that acknowledging the diagnosis is actually crucial to maintaining identity because it allowed people with dementia to understand why changes were occurring and attribute them to dementia instead of themselves.

The second area of impact was changing relationship, with couples describing the impact of dementia in terms of the changes to roles and responsibilities in their relationship. Couples were aware that these changes had created changes to the overall reciprocity within the relationship, as the person with dementia was inevitably less able to contribute. Couples' responses to this change to reciprocity highlighted the need to take an individualistic approach to couples' experience of dementia. For example, two carers who responded in the same way to a change in reciprocity, were met with very different reactions from their spouses. Therefore, the extent to which changes to reciprocity were problematic for couples was related to how the carers responded to these changes, and also how the person with dementia reacted to the carers' response.

The third area of impact was changing communication within the relationship. Certainly, there was evidence to support the widely held view that communication can be difficult in dementia, and furthermore, that effective communication was valued by couples facing dementia. For people with dementia in particular, they reported appreciating non-verbal communication from their spouses that signalled their love and understanding. However, this study went further to propose that whilst the literature supports the view that 'open' or 'open uncertain' methods of communication were thought to be most adaptive, this study found vast differences as to what constituted an acceptable level of communication for couples. Therefore, whilst 'open' communication undoubtedly worked wonderfully for some of the couples in this study, other couples had tended not to discuss issues and were quite happy with that arrangement. Thus, responses to dementia within couples were affected by their historical ways of communication which determined their expectations regarding what constituted an acceptable level of communication. It was proposed that communication within couples facing dementia should be thought of as a continuum from closed communication to open communication whilst acknowledging differing levels of expectation and acceptability.

Therefore, research question 1 revealed that couples were aware of the impacts of dementia, both as a disease, and also with regards to what it meant for them. These narratives were sometimes shared within couples, and others were more independent. However, this seemed to reflect the historical nuances of the relationship rather than being any statement about how successfully couples had managed the impact of dementia. Thus, this research question really highlighted that these findings reiterate the importance of respecting individual responses to dementia and therefore accepting that coping strategies should be considered for their efficacy on an individual basis, rather than assuming that one size fits all.

The second research question explored what coping strategies were employed by people with mild dementia and their spouses. Evidence for the successful use of both problem and emotion-focused coping strategies was found. This is

in-keeping with research into chronic illness and dementia specifically which proposes that both types of strategy are adaptive in these situations. Furthermore, this study developed previous work by suggesting that rather than being separate, strategies that help normalise the situation are intrinsically linked to those that help couples adjust. Indeed, there was evidence in this study that these two strategies were often used concurrently to good effect.

Certainly, awareness and understanding of dementia and its implications was of fundamental value for couples because it allowed them to put changes into context. This was not always easy, particularly for carers, but overwhelmingly, there was support for the importance of understanding. However, this study reports slightly different findings to previous research which suggests that shared awareness in couples is developed through awareness of memory difficulties and associated problems, awareness about how these problems may develop, and awareness about the impact of dementia on their spouse (Hellstrom et al 2005). Indeed, despite couples in this study generally demonstrating awareness on all three fronts as individuals, this did not necessarily mean that they developed a shared awareness. Again, this was related to how couples communicated historically, with most couples attempting to cope in the ways that came most naturally to them.

All couples, however, did share a desire to get on with their lives and regain and then maintain a sense of normality. There were four key ways in which this was achieved: development of positive cognitions, keeping active, lessening the load, and direct discussion and support.

Firstly, couples did develop and share positive cognitions such as optimism and downward comparisons. Although these strategies were again underpinned by understanding, couples acknowledged that they did not want to focus on the inevitability of the future, and instead focused on maintaining their sense of normality and making the most of the present. This can be likened to 'open uncertain' communication proposed as the most feasible open form of communication for couples facing dementia by Hellstrom et al (2005).

This study also made a contribution to the literature as the first to take a dyadic view of the impact of medication on coping. Certainly, couples were generally very positive about the medication and were keen to orator their experiences. Therefore, it is possible that medication may advantage couples in ways beyond its pharmaceutical benefit. Indeed, couples reported that it gave them hope and enabled them to regain parts of their lives that they thought they had lost. Furthermore, it also proved a valuable platform through which couples discussed different aspects of dementia. Therefore, medication was an important instrument for couples in developing positive cognitions.

Secondly, couples attempts to keep active often became the focus of their attention since this featured across their daily lives. Couples used routine in order to provide some structure to their days and weeks and to maximise the chance of the person with dementia retaining a sense of independent through taking part in practised activities. However, at the heart of keeping active strategies was that the person with dementia took part in *meaningful* activities that supported their sense of identity. This study found evidence to suggest that while people with dementia had insight into which activities were important to them, it was their carers who made their involvement in these activities a reality. Carers therefore acted for the greater good, for instance by sacrificing time on their own in order to ensure that they could provide a reassuring presence to their spouse. Therefore, there was a sense that carers fought to maintain an overall sense of normality for them and their spouse as a couple, rather than focusing on their own sense of normality. Furthermore, people with dementia responded well to their spouses' encouragement and motivation, which meant that strategies aimed at keeping active were often successful. This was important for couples since many of the strategies focused on meaningful activities which helped to uphold the person with dementia's sense of identity.

Furthermore, couples felt confident that they were well placed to implement coping strategies in ways that were appropriate for their spouse, and also reflected the style of coping which they had adopted as a couple over the years. Therefore, this suggests that couples are often in a unique position in

dementia because they likely have a good knowledge of their spouse, and as dementia most often occurs in later life, are often both retired and therefore have the opportunity to spend their time together if that is an appropriate coping strategy for them. Therefore, they may have access to certain coping strategies that are not afforded to other relationships such as parent-child.

Through the use of these strategies, couples accepted that although their lives were not 'normal' per se, they endeavoured to make them as normal as they could be. Therefore, keeping active strategies ensured that normality was not achieved at the expense of reality. In fact, this study has highlighted that couples actively used their awareness of dementia and their knowledge of their spouse in order to develop meaningful solutions which enabled them to focus on the positive aspects of their lives. This supports work by Cooper et al (2008) who proposed that key to coping with caregiving in dementia was the ability to recognise whether situations could be changed, and then implement problem-focused strategies for those that could be changed, and emotion-focused strategies for those that could not. Indeed, this study has revealed that couples' understanding of their partners enabled them to make these judgements in context of their partner and history together and therefore implement the most appropriate strategies.

The third way in which couples upheld a sense of normality was to lessen the load on each other. This study has provided a thorough understanding of the ways in which couples attempted to do this, particularly through the equal involvement of both partners in the research. Therefore, this study has made a novel contribution to the literature in terms of how this activity shapes the experience of mild dementia for couples. Lessen the load referred to partners being reluctant to discuss issues that they feared may upset their spouse, or contradict the sense of normality that they had worked hard to create. Furthermore, it referred to couples making attempts to do practical tasks without involving their spouse so as to lessen the load on them. Therefore, these activities were underpinned by an understanding that having mild dementia, or being married to someone with mild dementia, could be very

difficult. Thus, spouses made attempts to protect each other and make things as easy as possible.

Furthermore, couples used their knowledge of their spouse in order to choose the most appropriate ways of dealing with issues, such as using the right method of encouraging them to maintain involvement in activities. Moreover, couples used their knowledge of their spouse in order to understand their responses to dementia in the context of how they had responded to other stressful events in their lives. Furthermore, couples seemed to take strength from the ways in which they had dealt with previous events and often coped with dementia in ways that reflected how they had coped with life together over the years.

By its very essence, couples attempted to lessen the load with stealth which meant that commonly their spouses were unaware of their efforts. This was sometimes done purposely, for example, when carers were fearful of their spouses realising that they had deteriorated and were careful to engineer both their communication and behaviour in ways that would not reveal this.

Therefore, these protective strategies were useful for certain couples at certain times. However, there were other occasions in which it may have been useful for partners to be aware of their spouses' efforts, such as when carers described feeling upset that their spouse appeared to have no concern about the impact of dementia on them when in fact the person with dementia was making efforts to lessen the load on their spouse. Furthermore, these strategies often meant that partners lost a confidante in order to protect their spouses. This had implications for carers in particular who found this change in role sometimes difficult to adjust to.

The fourth, and last, way in which couples upheld a sense of normality was through direct discussion and support. Whilst subtle means of communication were useful, there was also evidence in this study that direct discussion was beneficial. Again, the extent to which direct communication strategies were accessed depended on the historical coping styles adopted by couples, although all couples used their knowledge of their coping styles and their

spouses in order to determine which communication styles they used. This study revealed two main positives which arise from direct discussion. One was that talking things through inadvertently reinforced the sense within couples that they were a team, and one partner discussing their concerns, encouraged the other partner to do the same. Second was that by airing their concerns, this allowed their partner to provide emotional support. This study therefore adds to the literature by suggesting that couples who share 'complimentary vulnerabilities' also reinforce their roles of husband and wife which ultimately helps reinforce their sense of normality. The usefulness of emotional support is also well reported in the literature. Couples in this study shared vulnerabilities both informally, for example through joking, as well as through more formal discussion about issues. Therefore, couples actively accessed the communication style that was most appropriate to them and used it in order to share vulnerabilities.

Therefore, research question 2 revealed that couples used their understanding of dementia, and their knowledge and understanding of their spouse in order to develop coping strategies that were effective and appropriate. There was evidence that couples used both problem and emotion-focused strategies and these were often used concurrently which added to their efficacy. Throughout this discussion, it has been noted that couples responded to dementia in ways that reflected their natural coping styles which had been developed over the years. Therefore, although as individuals they demonstrated awareness and understanding of dementia, this did not always mean that couples went on to develop a shared awareness. This was not indicative of 'good' or 'bad' coping but rather reflected the historical nuances of their relationship. Couples did, however, share positive cognitions, particularly with regards to medication. In fact, medication had several further benefits such as giving the couples hope, enabling them to regain parts of their lives they had thought lost, and also provided a valuable platform through which to discuss the impact of dementia. Couples' main motivation was to get on with their lives and to regain a sense of normality. This sense of normality was seen across couples and was fundamental in the development of coping strategies. Normality was achieved through activities that helped to keep them active, activities that helped to

lessen the load on their partners, and activities that afforded direct discussion and support. Throughout, there was evidence that these strategies were adopted according to each partners' knowledge and understanding of their spouse whereby strategies were adopted which would provide the best solution to dementia related challenges. Furthermore, the ways in which partners contributed to these strategies were also linked to their knowledge of their spouse to ensure maximum efficacy.

Therefore, that couples' responses to dementia have been previously presented as a series of discrete phases, did not seem appropriate here given that the differences in the couples' historical relationships had such a bearing on how they were now addressing the challenge of dementia. Thus, the last section of the discussion chapter introduced the idea of a continuum as best representative of couples' responses to dementia because this would allow for responses to be considered in context of what may be expected from different couples. For example, this would mean that their responses could be thought of in terms of their age, historical communication patterns, patterns of activity, and whether they tended to do things as a couple or individually. The ways in which this idea of a continuum fitted with the main four ways in which couples reported trying to maintain a sense of normality were presented and discussed.

8.5 Professional/practice implications

This study has demonstrated that overwhelmingly couples wanted to get on with their lives and maintain a sense of normality. It has shown that even with minimal professional interaction, couples instinctively adapted to dementia-related challenges with strategies borne out of understanding and appropriateness to them and their situation, both historically and presently. Keady et al (2007) argue that such insight into the ways in which people naturally cope is important for the development of suitable interventions.

There is value in involving health care professionals in order to help couples uphold a sense of normality in their lives, particularly where this helps couples

to maintain the person with dementia in the community if that is their wish. This is of course fundamental to individual couples, but must also be considered with regards to the wider picture. The UK Government, and indeed Governments across the world (Wimo and Prince 2010), are under increasing pressure to accommodate the increasing numbers of dementia cases that are inevitable over the coming decades, and an essential part of this process will be to provide interventions that best equip people with dementia and their carers to cope in the community for as long as is appropriate. This study suggests that these interventions should not so much take a blanket approach regarding which strategies are most efficacious, but rather to respect individual coping styles and aim to work with people with dementia and their carers in order to make the best of their coping strengths. Interventions should also be developed in acknowledgement of the personal costs to families facing dementia, but also in respect of the benefits associated with family caregiving, both for the person with dementia and the carer (Narayan et al 2001). Furthermore, Galvin et al (2005) proposed that research that represents the lived everyday experience of people with dementia and their carers should “become a pivotal source of iterative evidence for ongoing direction and practice development” (p.9).

Clarke (1999) referred to ‘maintenance’ activities that enable carers to continue to care in the community, and ‘movement’ strategies which encourage families to accept services as necessary. Although ‘movement’ strategies may be more pertinent in the moderate and late stages of dementia, it is possible that both strategies could be used concurrently since many couples require services in order to maintain the person with dementia in the community, such as help with personal care or a respite service in order to give the carer regular breaks. This study has shown that it is possible to live well with mild dementia, and is hopeful that in line with Government policy, healthcare professionals can develop a role through which they can help couples to put both maintenance and movement strategies into context, that is that they exist in order for couples to live well with dementia.

Furthermore, this study has highlighted the positive impact of acetylcholinesterase inhibitors in the experience of dementia for couples, and thus the importance of improving our understanding of how the use of these medications can improve couples' coping repertoires. This is supported by Bullock (2004) who reported that successful treatment of the person with dementia is associated with improved quality of life for the carer and a decrease in care home admissions. Thus, in line with the needs of Government as well as individual couples facing dementia, it is in everyone's favour to develop research in this area and improve appreciation among healthcare professionals surrounding the potential additional benefits of acetylcholinesterase inhibitors.

Some interventions with the aim for people with dementia and their families to live well with dementia have been developed over the last ten years, such as support groups. Locally, we have a group called 'Think Again' which is run for people diagnosed with Mild Cognitive Impairment or dementia and their carers (O'Hare 2009). The group runs for eight weeks during which attendees cover a number of subjects related to dementia with members from a multi-disciplinary team, such as Occupational Therapists, Psychologists, Speech and Language Therapists, a Drama Therapist and an Art Therapist. An important part of this process is to meet other people going through the same experience. A support group for carers is also run by the Memory Clinic Carer Support Workers, which covers a number of topics and works with carers to help them come to terms with dementia and develop successful coping strategies for practical and emotional challenges associated with caring for someone with dementia. Finally, there is also a centre specifically for younger people with dementia called the 'Forget Me Not Centre' which counts activities such as sailing and hiking in its repertoire. The need for specific interventions for younger people with dementia was also advocated by Reed, Clarke, Cantley and Stanley (2007). Therefore, these interventions help individuals, couples and families to come to terms with dementia and encourage them to implement strategies that can help them live well with dementia.

However, there currently lacks a 'catch all' element to post-diagnostic interventions whereby people who are diagnosed with dementia do not have *automatic* access to post-diagnostic support. Furthermore, it may be that an individual intervention is more beneficial for some clients and their families, such as discussing their diagnosis with a healthcare professional specifically in order to help them to recognise and work with their strengths in order to live well with dementia (Yarry et al 2010). Indeed, this approach is strongly supported by the findings of this study which emphasised the individualised responses from couples to what was essentially the same stressor: dementia. Recent research has seen the development of a more individualised approach to dementia care, such as Co-Constructed Inquiry. This approach sees a healthcare professional work with someone with dementia in order to create their 'life story script' (Keady et al 2007), and therefore understand their responses to dementia in the context of their life and also in terms of how they have responded to stressful events throughout their lives. The evaluative component of this intervention may also be conducive for couples facing dementia, since couples in this study reported that evaluating their lives helped them to create positive cognitions and also understand the responses of their spouses. Furthermore, spontaneously engaging in life evaluation was also found by Daniels et al (2007) who interviewed one couple over a six month period. Indeed, working with couples' strengths is advocated by a recent paper from Yarry et al (2010) who developed an intervention for dyads facing mild to moderate dementia. The authors identified existing strengths and used these to develop new skills which facilitated efficacious coping. Therefore, individual interventions that help couples to make sense of dementia in context of their lives may be one way in which services can help couples to uphold their aims of getting on with their lives, maintaining a sense of normality, and essentially living well with dementia.

This is also advocated by the UK Dementia Strategy who proposed that both individual and group post-diagnostic support should become a central part of secondary care's responsibility with regards to the care for those with dementia. Therefore, this study has addressed Objective 2 of the UK Dementia Strategy 2009 (Good-quality early diagnosis and intervention for all) by

emphasising the importance of couples facing dementia having access to interventions which are tailored to respect individual responses and coping styles and to work with individuals and families in order to maximise their strengths in coping with dementia.

Furthermore, it is important that clinicians include family members in interventions since “serious health problems challenge the quality and maintenance of relationships with family and friends at the same time that such relationships play a pivotal role in coping with illness” (Lyons et al 1995, p1.). Moreover, Daniels et al (2007) reported that NICE acknowledged that the impact of dementia on relationships is a ‘core principle of care’ for the Health Service. This is supported by the findings of this study that saw the carers playing a pivotal role not only in upholding the involvement of their spouse in meaningful activities, but also doing this in a way that was respectful and appropriate to their spouse and therefore least likely to cause upset. Therefore, this study has also addressed Objective 16 of the Strategy (A clear picture of research evidence and needs) by investigating a gap in the literature with regards to the lived experience of dementia within couples. This study has done this by simultaneously exploring the perspectives of both the person with dementia and their carer which has unearthed new findings about how couples respond to dementia. This study was presented at the UK Dementia Congress in 2009 and its results will be prepared for publication in a peer-reviewed journal.

8.6 Limitations

This study has limitations regarding its small sample size, meaning that caution should be heeded when discussing these findings in terms of the wider picture. Furthermore, this sample was limited to people whose ethnicity was ‘White British’ and therefore offers only limited insight into the lived experience of people with other ethnic backgrounds. The couples in this thesis were also all married and of the generation that meant that they had been married for many years, even though some were second marriages. As society develops and divorce rates rise, the kind of couples who face dementia may change in the

coming decades. Therefore, the findings of this study are limited to the participants of this study who were heterosexual white, British couples in long-term relationships. Thus, although the spouses of people with dementia were referred to as 'carers' throughout this study, it is important to remember that the results of this study are pertinent only to spouse carers and not other family members or formal carers.

However, this study does perform an important function in research, which is to yield rich data about the sample in question. This is in keeping with the methodological approach of the study which promotes the idea of interviewing a 'closely defined group for whom the research question will be significant' (Smith and Osborn 2003, p.56) through the use of the methodological approach of Interpretative Phenomenological Analysis (Smith, Jarman and Osborn 1999). Therefore, although these results cannot be generalised, they do help to further understanding of the nuances involved in the lived experience of dementia for couples, which was the aim of this thesis.

Semi-structured interviews were conducted in order to maximise the participant's opportunity to tell their story of their experiences whilst addressing the issues that were pertinent to this thesis. One disadvantage of this style of interviewing is that the interviewer has less control over the interview than would be the case during a structured interview, and as such semi-structured interviews can take longer to carry out and analyse (Smith and Osborn 2003). Whilst this may be a disadvantage in some areas of research, these factors were actually key elements to the success of this study. For example, it was imperative that the participants of this study felt that they could discuss whatever they felt was relevant, and taking our time over the interviews gave the interviewer and interviewee time to develop this rapport.

The lack of a control group may also be seen as a limitation of this study because there was no comparison between the sample of this study and couples with a different chronic illness, or well couples. Therefore, it is difficult to be certain that the findings of this study represent the lived experience of

mild dementia specifically as opposed to the generic lived experience of chronic illness.

Methodologically, people with dementia have not been readily included in research due to questions of consent and reliability. Their involvement in this study could be seen as a limitation since the content of their interviews may have been factually incorrect, and no attempts were made to triangulate the content of their interviews with their carers. However, the theoretical perspectives that underpin this thesis are concerned with understanding the subjective world of the individual, and thus not with facts. Furthermore, interviews were conducted separately with people with dementia and their carers in order to allow them to speak freely about their experiences without worrying about hurting their spouses' feelings. Therefore, it would have been neither useful nor ethical to double check transcripts with anyone apart from the interviewee. Therefore, all interviews were summarised and checked with the interviewee in order to ensure that the researcher had correctly understood their meaning.

The importance of interviewing couples separately and being mindful as to the content of the summary letters was brought up by one carer who had talked openly to the researcher about her feelings, and was aware that her husband would be upset if he read about everything that was discussed during the interview. In this case, the researcher wrote two summary letters for each of this carer's interviews. Before both the second interview and the final meeting, the carer was sent the shortened summary letter which included all of the 'non-sensitive' data. When the researcher conducted the second interview and final meeting with the carer, she showed her the whole summary letter which the carer read. Any thoughts and discrepancies were then discussed. Although it is not ideal that this carer was treated differently, it was felt that her well-being, and that of her husband, was far more important.

Although the interviews began with a discussion about their relationship over the years, the conversation was mainly focused around dementia. Therefore, this study may be limited in its understanding of how the couples' relationships

functioned before dementia and how each couple had responded to previous stressful events in their lives.

Furthermore, couples described their conscious thought processes regarding dementia, and therefore they may have been employing further strategies albeit subconsciously, which this study may not have accessed. However, the aim of this thesis was to understand the lived experience of dementia, which arguably centres upon couples conscious thoughts, as do the theoretical perspectives which underpin it.

8.7 Further research

Research which addresses the lived experience of couples from other ethnic backgrounds should be conducted in order to improve understanding of the natural ways in which different ethnicities consider dementia and the ways in which they cope with it. This knowledge is particularly important if clinicians are to work with clients and their families in order to make the best of their natural coping styles. Future research should also aim to improve our knowledge of the lived experience of dementia for younger people facing dementia as well as considering the impact of dementia on other family members such as adult-children and grandchildren.

Future research could use a combination of joint and individual interviews to combine advantages from both methods (Albitt et al 2009). The joint interview provides information regarding communication and interactions and reassurance for the interviewees, but individual interviews provide a platform to discuss whatever they want without fear of offending their partner. This approach would be useful in order for researchers to explore issues brought up in joint interviews with both partners separately.

Furthermore, researchers have proposed that interviews conducted over time are useful for establishing trust (Keady et al 2007, Daniels et al 2007). Interviews conducted over time may also provide insight into the longitudinal experience of dementia, an understanding of which is as yet lacking in the

literature (Caddell and Clare 2010). Whilst this study has highlighted how coping styles in mild dementia are adapted to reflect historical ways of coping for couples, further research may investigate whether coping styles change as the disease progresses. Indeed, research suggests that strategies used by carers change from problem-focused to emotion-focused in response to an increased dependency from the person with dementia (Matson 1994), but the literature has not investigated how these changes are managed within couples.

An important finding in this thesis was that couples attempted to lessen the load on each other. These strategies often worked well, but sometimes it may have been more efficacious for coping if partners had been aware of their spouses' efforts. Future research should therefore endeavour to determine whether partners being made aware of their partners' efforts would be beneficial to couples' overall coping.

8.8 Conclusion

This study has contributed to the literature by simultaneously exploring the perspectives of both people with dementia and their spouses with regards to their lived experience of dementia. This has allowed findings to be explained in context of their relationship, which has highlighted new contributions to the field.

Couples described their experience of dementia as a process, which could be mapped onto the chronological events that took place, such as diagnosis. Couples demonstrated their awareness of the impact of dementia both on themselves and on their spouses, and made attempts to understand why it had happened. Following the diagnosis and the heightened emotions associated with it, couples overwhelmingly wanted to get on with their lives, and to regain and maintain a sense of normality.

This study revealed the ways in which couples supported each other to develop positive cognitions. Medication proved a useful medium for couples

through which to discuss how they were coping, and furthermore provided couples with a sense of hope because they were able to regain some parts of their lives which they feared lost.

Furthermore, although couples maintained a sense of normality, they did not do so at the expense of reality and in fact, understanding and awareness underpinned many of the strategies adopted by couples. Strategies that allowed couples to keep active were a fundamental part of their overall coping, particularly as these strategies had a bearing on day to day life. This study revealed that carers played an essential role in ensuring that their spouse continued to be involved in meaningful activities which enhanced their sense of identity. This role was two-fold since carers were well placed, as husbands or wives of the person with dementia, to know what activities would constitute meaningful, and also that carers gave their encouragement in ways that were appropriate given their knowledge of their spouse and their role in the historical relationship with their spouse. By acting in ways that were in-keeping with previous roles, this helped to maintain a sense of normality.

This study also identified the use of strategies that lessened the load whereby both people with dementia and their carers, being aware of the difficulties caused by dementia, made attempts to protect their spouse. Thus, as these strategies were designed to protect their spouse, these efforts often went unnoticed by their partners. In some cases, this appeared to be conducive to overall coping, but in other cases, it may have been beneficial for partners to be aware of their spouses' efforts.

A further contribution to the literature was made with regards to direct discussion and support. Couples in this study reported on the importance of emotional support from their spouse, which again added to their sense of normality. This study identified that couples achieved this by sharing vulnerabilities, which both encouraged their spouse to do the same and allowed the receiving spouse to offer emotional support.

Therefore, the lived experience of couples in this study was grounded in an understanding of dementia as a disease and what it meant for them. Couples were eager to get on with their lives and maintain a sense of normality, although not at the expense of accepting the reality nor upsetting their spouse. Thus, couples developed ways of coping that reflected their natural coping style, which allowed couples to maintain a sense of normality. Furthermore, both partners made attempts to lessen the load on their partner, thus reducing the impact of dementia overall. Where couples shared vulnerabilities, this also enabled couples to maintain their roles of husband and wife, thus diminishing the impact of dementia further. However, the extent to which couples communicated openly was more related to their previous communication styles than how well they had adapted to dementia. Therefore, researchers and clinicians must remember that responses to dementia are vastly individualised and attempts to provide interventions which support couples facing dementia, should take this into account. Thus, this thesis has introduced the notion of a relationship continuum through which to understand couples' responses to dementia. This acknowledges that couples have different pre-morbid relationship styles and thus will have different expectations about the impact of dementia and how they might cope with it.

- **Chapter 8** discussed the results of this thesis in the context of the literature. Furthermore, professional/practice implications, limitations of this study and suggestions for further research were discussed.
- Literature suggests that changing roles and responsibilities will impact on levels of reciprocity in couple relationships. This study offers further evidence that crucially it is how carers reacted to dementia and also how their reactions were received by their spouses which determined feelings of reciprocity. This emphasises the importance of taking individualised approach to understanding the lived experience of dementia since similar reactions from carers can be taken in different ways by people with dementia.
- This study also contributed to research into awareness in couples facing dementia which proposed that shared awareness is the key to successful coping. The results of this study in fact show that couples who continued to cope in the ways that they had done historically, even if that was independently, fared better than those who had changed their coping styles.
- This study offered a unique insight into the experience of medication for couples. Three benefits in addition to the pharmacological benefit, were identified by couples. First, medication gave couples hope, second, the perceived halt gave couples the chance to regain parts of their lives they had thought lost, and lastly medication proved a good platform through which to discuss issues about dementia.
- Keeping active was key to couples maintaining a sense of normality. Carers were essential to the success of maintaining meaningful involvement of their loved one. They used their knowledge of their spouse in order to both choose appropriate activities and implement them in such a way that would suit their spouse. Thus, carers focused on maintaining a sense of normality of them as a couple, but often at the expense of their own normality.
- The use of a relationship continuum as an idea through which to understand how couples respond to dementia was presented. This acknowledges the inherent differences in couples' pre-morbid relationship styles which mean that they will have different expectations about the experience of dementia and the roles within their relationship.
- Professional and practice implications were discussed and the importance of work into the lived experience of dementia in terms of policy was presented. In particular, it was highlighted that individualised interventions may be useful in order to help couples identify their strengths and ways of coping that are appropriate for them.
- Limitations of this study were also discussed.
- Suggestions for further research were proposed.

References

Ablitt, A., Jones, G.V., Muers, J. (2009) Living with dementia: A systematic review of the influence of relationship factors. *Aging and Mental Health*, 13 (4), 497-511.

Aldwin, C.M. (1994) *Stress, coping and development: An integrative perspective*. Guildford Press: New York.

Almberg, B., Grafstrom, M., Winblad, B. (1997) Major strain and coping strategies as reported by family members who care for aged demented relatives, *Journal of Advanced Nursing*, 26, 683-691.

Alzheimer's Society (2004) Drugs for the treatment of Alzheimer's disease. London: Alzheimer's Society.

Alzheimer's Society statistics (2007) Alzheimer's Society.

Alzheimer's Society (2010) Online factsheets. Alzheimer's Society.

Andersen, C.K., Wittrup-Jensen, K.U., Lolk, A., Andersen, K., Kragh-Sorensen, P. (2004) Ability to perform activities of daily living is the main factor affecting quality of life in patients with dementia, *Health and Quality of Life Outcomes*, 2, 52.

Arksey H, Hepworth D, Qureshi H. (2000) *Carers' needs and the Carers Act: An evaluation of the process and outcomes of assessment*. Social Policy Research Unit, York: University of York.

Bahro, M., Silber, E. and Sunderland, T. (1995) How do patients with Alzheimer's Disease cope with their illness?- A Clinical Experience Report. *Journal of American Geriatrics Society*, 43, 41-6.

- Baider, L., Kaufman, B., and Peretz, T. (1996). Mutuality of fate: adaptation and psychological distress in cancer patients and their partners. In L. Baider, C. Cooper, & A. Kaplan-De Nour (Eds.) *Cancer and the Family*. John Wiley & Sons Ltd: New York.
- Baikie, E. (2002) The impact of dementia on marital relationships, *Sexual and Relationship Therapy*, 17 (3), 289-299.
- Beard, R.L. (2004) In their voices: Identity preservation and experiences of Alzheimer's disease, *Journal of Aging Studies*, 18, 415-428.
- Bender, M.P., Cheston, R. (1997) Inhabitants of a lost kingdom: A model of the subjective experiences of dementia, *Aging and Society*, 17, 513-532.
- Berg-Weger, M., McCartland Rubio, D., Tebb, S.S. (2001) Strengths-based Practice With Family Caregivers of the Chronically Ill: Qualitative Insights. *Families in Society: The Journal of Contemporary Human Services*, 82 (3), 263-272.
- Blanchard, C.G., Albrecht, T.L., Ruckdeschel, J.C. (1997) The Crisis of Cancer: Psychological Impact on Family Caregivers. *Oncology*, 11 (2), 189-194.
- Bourgeois, M.S., Schulz, R. and Burgio, L. (1996) Interventions for caregivers of patients with Alzheimer's Disease: A review and analysis of content, process and outcomes. *International Journal of Aging and Human Development*, 43 (1), 35-92.
- Bramwell, L. (1986) Wives' experiences in the support role after husbands' first myocardial-infarction. *Heart and Lung*, 15 (6), 578-584.
- Braun, M., Scholz, U., Bailey, B., Perren, S., Hornung, R., Martin, M. (2009) Dementia caregiving in spousal relationships: A dyadic perspective. *Aging and Mental Health*, 13 (3), 426-436.

Brown, A. and Roch, P. (2010) My husband has young-onset dementia: A daughter, wife and mother's story. *Dementia*, 9 (4), 451-453.

Bullock, R. (2004) The needs of the caregiver in the long-term treatment of Alzheimer's disease. *Alzheimer Disease and Associated Disorders*, 18, S17-S23.

Burns, A., Jacoby, R. and Levy, R. (1990) Psychiatric phenomena in Alzheimer's disease. 3. Disorders of mood. *British Journal of Psychiatry*, 157, 81-86.

Caddell, L.S. and Clare, L. (2010) The impact of dementia on self and identity: A systematic review. *Clinical Psychology Review*, 30, 113-126.

Carpenter, B.D., Mak. W. (2007) Caregiving couples. *Generations*, 31, 47-53.

Charlesworth, G., Tzimoula, X., Higgs, P. and Poland, F. (2007) Social networks, befriending and support for family carers of people with dementia. *Quality in Ageing*, 8 (2), 37-45.

Chatterjee A., Strauss M.E., Smyth K.A. and Whitehouse P.J. (1992) Personality changes in Alzheimer's Disease. *Archives of Neurology*, 49, 486-91.

Clare, L. (2002) We'll fight as long as we can: coping with the onset of Alzheimer's Disease. *Aging and Mental Health*, 6, 139-48.

Clare, L. (2002) Developing awareness about awareness in early-stage dementia: the role of psychological factors. *Dementia*, 1 (3) 295-312.

Clare, L. (2003) Managing threats to self: awareness in early stage Alzheimer's disease. *Social Science and Medicine*, 57, 1017-1029.

Clark, M.S. and Bond, M.J. (2000) The effect on lifestyle activities of caring for a person with dementia. *Psychology, Health and Medicine*, 5 (1): 13-27.

Clarke, C.L. (1999) Family care-giving for people with dementia: Some implications for policy and professional practice. *Journal of Advanced Nursing*, 29 (3), 712-720.

Clarke C. and Watson D. (1991) Informal carers of the dementing elderly: A study of relationships. *Nursing Practice*, 4, 17-21.

Clarke, C.L., Keady, J., Wilkinson, H., Gibb, C.E., Luce, A., Cook, A. and Williams, L. (2010) Dementia and risk: contested territories of everyday life. *Journal of Nursing and Healthcare of Chronic Illness*, 2, 102-112.

Coen, R.F., Swanwick, G.R.J., O'Boyle, C.A. and Coakley, D. (1997) Behaviour disturbance and other predictors of carer burden in Alzheimer's Disease. *International Journal of Geriatric Psychiatry*, 12, 331-336.

Cohen, D., Kennedy, G. and Eisdorfer, C. (1984) Phases of change in the patient with Alzheimer's Dementia: A conceptual dimension for defining health care management. *Journal of the American Geriatrics Society*, 32 (1), 11-15.

Cooper, C., Katona, C., Orrell, M. and Livingston, G. (2008) Coping strategies, anxiety and depression in caregivers of people with Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 23, 929-936.

Cousins, R., Davies, A.D.M., Turnbull, C.J. and Playfer, J.R. (2002) Assessing caregiving distress: A conceptual analysis and a brief scale. *British Journal of Clinical Psychology*, 41, 387-403.

Coyne, J.C. and Smith, D.A.F. (1991) Couples coping with myocardial-infarction – A contextual perspective on wives' distress. *Journal of Personality and Social Psychology*, 61 (3), 404-412.

Coyne, J.C., Aldwin, C. and Lazarus, R.S. (1981) Depression and coping in stressful episodes. *Journal of Abnormal Psychology*, 90 (5), 439-447.

Cumming, E. and Henry, W.E. (1961) *Growing old: The process of disengagement*. New York: Basic Books.

Cummings, J.L., Schneider, L., Tariot, P.N., Kershaw, P.R., Yuan, W. (2004) Reduction of behavioural disturbances and caregiver distress by galantamine in patients with Alzheimer's disease. *The American Journal of Psychiatry*, 16 (3), 532-538.

Daniels, K.J., Lamson, A.L., Hodgson, J. (2007) An exploration of the marital relationship and Alzheimer's Disease: One couple's story. *Families, Systems and Health*, 25 (2), 162-177.

Davies, J., Gregory, D. (2007) Entering the dialogue: Marriage biographies and dementia care. *Dementia*, 6 (4): 481-488.

De Boer, M.E., Hertogh, C.M.P.M., Droes, R-M., Riphagen, I.I., Jonker, C. and Eefsting, J.A. (2007) Suffering from dementia – the patient's perspective: a review of the literature. *International Psychogeriatrics*, 19 (6), 1021-1039.

De Ridder, D.T.D., Schreurs, K.M.G. and Kuijer, R.G. (2005) Is spousal support always helpful to patients with asthma or diabetes? A prospective study. *Psychology and Health*, 20 (4), 497-508.

de Vugt, M. (2003) Behavioural disturbances in dementia patients and quality of the marital relationship. *International Journal of Geriatric Psychiatry*, 18, 149-154.

DeLongis, A. and Holtzman, S. (2005) Coping in context: The role of stress, social support and personality in coping. *Journal of Personality*, 73 (6), 2-24.

DeLongis, A. and O'Brien, T. (1990) An interpersonal framework for stress and coping: An application to the families of Alzheimer's patients. In Stephens, M.A.P., Crowther, J.H., Hobfoll, S.E. and Tennenbaum, D.L. (Eds.) *Stress and Coping in Later Life Families*. New York: Hemisphere Publishing Corporation.

Department of Health (2001) *National Service Framework for Older People*. London: Department of Health.

Department of Health (2004) definition of chronic disease.

Department of Health (2005) *Everybody's Business*. London: Department of Health.

Department of Health (2009) *UK National Dementia Strategy: Living well with dementia*. London: Department of Health.

Dickson, A., Knussen, C. and Flowers, P. (2008) "That was my old life; it's almost like a past life now": Identity crisis, loss and adjustment amongst people living with chronic fatigue syndrome. *Psychology and Health*, 23 (4), 459-476.

Downs, M. (1997) The Emergence of the Person with Dementia Research. *Aging and Society*, 17, 597-607.

Eagles, J.M., Craig, A., Rawlinson, F., Restall, D.B., Beattie, J.A.G, Besson, J.A.O. (1987) The Psychological Well-being of Supporters of the Demented Elderly. *British Journal of Psychiatry*, 150, 293-298.

Eloniemi-Sulkava, U., Notkola, I-L., Hamalainen, K., Rahkonen, T., Viramo, P., Hentinen, M., Kivela, S-L., Sulkava, R. (2002) Spouse Caregivers' Perceptions of Influence of Dementia on Marriage. *International Psychogeriatrics*, 14 (1), 47-58.

Epp, T.D. (2003) Person-centred Dementia Care: A Vision to be Refined. *The Canadian Alzheimer Disease Review*, p.14-18.

Epping-Jordan, J.E., Compas, B.E., Osowiecki, O.M., Oppedisano, G., Gerhardt, C., Primo, K. and Krag, D.N. (1999) Psychological adjustment in breast cancer: Processes of emotional distress. *Health Psychology*, 18, 315-326.

Fade, S. (2004) Using interpretative phenomenological analysis for public health nutrition and dietetic research: a practical guide. *Proceedings of the Nutrition Society*, 63, 647-653.

Folkman, S., Lazarus, R.S., Dunkel-Schetter, C., DeLongis, A., Gruen, R.J. (1986) Dynamics of a stressful encounter: cognitive appraisal, coping and encounter outcomes. *Journal of Personality and Social Psychology*, 50 (5), 992-1003.

Folstein M.F., Folstein S.E., McHugh P.R. (1975) "Mini-mental state": A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12 (3), 189–98.

Fontana, A. and Frey, J.H. (2000) The interview: From structured questions to negotiated text. In Denzin, N. and Lincoln, Y. (Eds.) *Handbook of Qualitative Research*. London: Sage Publications Inc.

Forbat, L. and Henderson, J. (2003) "Stuck in the middle with you": The ethics and process of qualitative research with two people in an intimate relationship. *Qualitative Health Research*, 13 (10), 1453-1462.

Furlong, K.E. and Wuest, J. (2008) Self-care behaviours of spouses caring for significant others with Alzheimer's disease: The emergence of self-care worthiness as a salient condition. *Qualitative Health Research*, 18 (12), 1662-1672.

Galasinski, D. and Kozłowska, O. (2010) Questionnaires and the lived experience: Strategies of coping with the quantitative frame. *Qualitative Inquiry*, 16 (4), 271-284.

Gallagher-Thompson, D., Dal Canto, P.G., Jacob, T. and Thompson, L. (2001) A comparison of marital interaction patterns between couples in which the husband does or does not have Alzheimer's disease. *Journal of Gerontology*, 56B (3), S140-S150.

Galvin, K., Todres, L., Richardson, M. (2005) The intimate mediator: a carer's experience of Alzheimer's. *Scandinavian Journal of Caring Sciences*, 19, 2-11.

Garand, L., Dew, M.A., Eazor, L.R., DeKosky, S.T., Reynolds, C.F. 3rd (2005) Caregiving burden and psychiatric morbidity in spouses of persons with mild cognitive impairment. *International Journal of Geriatric Psychiatry*, 20(6), 512-522.

Garner J. (1997) Dementia: An intimate death. *British Journal of Medical Psychology*, 70, 177-84.

Gates, K. (2000) The experience of caring for a loved one: a phenomenological study. *Nursing Science Quarterly*, 13, 54-59.

George, C. and West, M. (1999) Developmental vs. social personality models of adult attachment and mental ill health. *British Journal of Medical Psychology*, 72 (3), 285-303.

Gilhooly, M.L.M. (1984) The impact of care-giving on care-givers: Factors associated with the psychological well-being of people supporting a dementing relative in the community. *British Journal of Medical Psychology*, 57, 35-44.

Gilhooly, M.L.M. (1986) Senile dementia: Factors associated with caregivers' preference for institutional care. *British Journal of Medical Psychology*, 59 (2), 165-171.

Gladstone, J.W. (1995) The marital perceptions of elderly persons living or having a spouse living in a long-term care institution in Canada. *The Gerontologist*, 35 (1), 52-60.

Graham, C., Ballard, C., Sham, P. (1997) Carers' knowledge of dementia, their coping strategies and morbidity. *International Journal of Geriatric Psychiatry*, 12, 931-936.

Halford, W.K., Scott, J.L. and Smythe, J. (2000) Couples and coping with cancer: Helping each other through the night. In Schmaling, K.B. and Goldman Sher, T. (Eds.) *The Psychology of Couples and Illness: Theory, Research and Practice*. Washington DC: American Psychological Association.

Harman, G. and Clare, L. (2006) Illness representation and lived experience in early-stage dementia. *Qualitative Health Research*, 16, 484-502.

Hayes, J., Zimmerman, M.K., Boylstein, C. (2010) Responding to symptoms of Alzheimer's disease: Husbands, wives, and the gendered dynamics of recognition and disclosure. *Qualitative Health Research*, 20 (8), 1101-1115.

Hellstrom, I., Nolan, M., Lundt, U. (2005) Awareness context theory and the dynamics of dementia: Improving understanding using emergent fit. *Dementia*, 4 (2): 269-295.

Hellstrom, I., Nolan, M., Lundt, U. (2005) 'We do things together': A case study of 'couplehood' in dementia. *Dementia*, 4 (1), 7-22.

Hellstrom, I., Nolan, M., Nordenfelt, L., Lundt, U. (2007) Ethical and methodological issues in interviewing persons with dementia. *Nursing Ethics*, 14 (5), 608-619.

Hubbard, G., Cook, A., Tester, S., Downs, M. (2002) Beyond words: Older people with dementia using and interpreting nonverbal behaviour. *Journal of Aging Studies*, 16 (2), 155-167.

Hubbard, G., Downs, M.G., Tester, S. (2003) Including older people with dementia in research: challenges and strategies. *Aging and Mental Health*, 7 (5), 351-362.

Hutchings, D., Vanoli, A., McKeith, I., Brotherton, S., Mcnamee, P., Bond, J. (2010) Good days and bad days: The lived experience and perceived impact of treatment with cholinesterase inhibitors for Alzheimer's disease in the United Kingdom. *Dementia*, 9, 409-425.

Ingebretsen, R. and Solem, P.E. (1998) Death, dying and bereavement. In Nordhus, I.H., VandenBos, G.R., Berg, S. and Fromholt, P. (Eds.) *Clinical Geropsychology*. Washington DC: American Psychological Association.

Ingebretsen, R., Solem, P.E. (2002) Attachment, loss and coping in caring for a dementing spouse. In, B. Miesen, G. Jones (Eds) *Care giving in dementia – Research and Applications*. London: Routledge.

Jones, P.S., Martinson, I.M., (1992) The experience of bereavement in caregivers of family members with Alzheimer's Disease. *Journal of Nursing Scholarship*, 24 (3), 172-176.

Kahan, J., Kemp, B., Staples, F.R. and Brummelsmith, K. (1985) Decreasing the burden in families caring for a relative with a dementing illness: A controlled study. *Journal of the American Geriatrics Society*, 33 (10), 664-670.

Kaplan, L. (2001) A Couplehood Typology for Spouses of Institutionalised Persons with Alzheimer's Disease: Perceptions of "We" – "I". *Family Relations*, 50 (1), 87-98.

Keady (1999) The dynamics of dementia: A modified grounded theory study. PhD thesis, University of Wales, Bangor.

Keady, J., Nolan M. (1994) Younger onset dementia: developing a longitudinal model as the basis for research agenda and as a guide to interventions with sufferers and carers. *Journal of Advanced Nursing*, 19, 659-669.

Keady, J., Nolan, M. (1995) IMMEL: assessing coping responses in the early stages of dementia. *British Journal of Nursing*, 4 (6), 309-314.

Keady, J., Nolan, M. (1995) IMMEL 2: working to augment coping responses in early dementia. *British Journal of Nursing*, 4 (7), 377-380.

Keady, J., Nolan, M. (2003) The dynamics of dementia: working together, working separately or working alone? In Nolan, M, Lundt, U., Grant, G. and Keady, J. (Eds.) *Partnerships in Family Care*. Open University Press.

Keady, J., Williams, S., Hughes-Roberts, J. (2007) Making mistakes – Using co-constructed inquiry to illuminate meaning and early adjustment to Alzheimer's Disease – A single case study. *Dementia*, 6 (3), 343-364.

Kirsi, T., Hervonen, A., Jylha, M. (2004) Always one step behind: husband's narratives about taking care of their demented wives. *Health: An International Journal for the Social Study of Health, Illness and Medicine*, 8 (2), 159-181.

Kitwood, T. (1993) Towards a theory of dementia care: The interpersonal process. *Ageing and Society*, 13 (1), 51-67.

Kitwood, T. (1997) *Dementia reconsidered: the person comes first*. Buckingham, Open University Press.

Knaf, K.A., Gilliss, C.L. (2002) Families and Chronic Illness: A Synthesis of Current Research. *Journal of Family Nursing*, 8 (3), 178-198.

Knapp M., Prince M., Albanese E. et al (2007). *Dementia UK: The full report*. London: Alzheimer's Society.

Knop B, Bergman-Evans B, and Wharton McCabe B. (1998) In sickness and in health: An exploration of the perceived quality of the marital relationship, coping and depression in caregivers of spouses with Alzheimer's Disease. *Journal of Psychosocial Nursing*, 36, 16-21.

Koski, L.R., Shaver, P.R. (1997) Attachment and Relationship Satisfaction across the Lifespan, Chapter 2. In R.J. Sternberg and M. Hojjat (Eds) *Satisfaction in Close Relationships*. London: The Guildford Press.

Kralik, D. (2002) The quest for ordinariness: transition experienced by midlife women living with chronic illness. *Journal of Advanced Nursing*, 39 (2), 146-154.

Kralik, D., Brown, M., Koch, T. (2000) Women's experiences of 'being diagnosed' with a long-term illness. *Journal of Advanced Nursing*, 33 (5), 594-602.

Kramer, B.J. (1993) Expanding the conceptualisation of caregiver coping: the importance of relationship-focused coping strategies. *Family Relations*, 42 (4), 383-391.

Laakkonen, M-L, Raivio, M. M., Eloniemi-Sulkava, U., Saarenheimo, M., Pietila, M., Tilvis, R.S., Pitkala, K.H. (2008) How do elderly spouse care givers of people with Alzheimer disease experience the disclosure of dementia diagnosis and subsequent care? *Journal of Medical Ethics*, 34: 427-430.

Langner, S.R. (1995) Finding meaning in caring for elderly relatives: Loss and personal growth. *Holistic Nursing Practice*, 9, 75-84.

Lewis, R.D.H. (1998) The impact of the marital relationship on the experience of caring for an elderly spouse with dementia. *Ageing and Society*, 18, 209-231.

LoboPrabhu, S., Molinari, V., Arlinghaus, K., Barr, E., Lomax, J. (2005) Spouses of patients with dementia: how do they stay together 'Till death do us part'? *Journal of Gerontological Social Work*, 44 (3/4), 161-174.

Lyons, R.F., Sullivan, M.J.L., Ritvo, P.G. (1995) *Relationships in Chronic Illness and Disability*, London: Sage Publications Ltd.

Maguire, M. (1999) Treating the dyad as the Unit of Analysis: A Primer on Three Analytic Approaches. *Journal of Marriage and Family*, 61 (1), 213-223.

Mahrer-Imhof, R., Hoffman, A., Froelicher, E.S. (2007) Impact of cardiac disease on couples' relationships. *Journal of Advanced Nursing*, 57 (5), 513-521.

Mann, C., Dieppe, P. (2006) Different patterns of illness-related interaction in couples coping with Rheumatoid Arthritis. *Arthritis and Rheumatism (Arthritis Care and Research)*, 55 (2), 279-286.

Markiewicz D, Reis M. and Gold D.P. (1997) An exploration of attachment styles and personality traits in caregiving for dementia patients. *International Journal of Aging and Human Development*, 45 (2), 111-132.

Martire, L.M., Stephens, M.A.P., Druley, J.A. and Wojno, W.C. (2002) Negative reactions to received spousal care: predictors and consequences of miscarried support. *Health Psychologist*, 21 (1), 167-76.

Marwit, S.J., Meuser, T.M., Bryer, D.E. (2005) Development of an awareness context theory typology for addressing communication patterns in mild dementia. *Clinical Gerontologist*, 28 (4): 61-80.

Matson, N. (1994) Coping, caring and stress: A study of stroke carers and carers of older confused people. *British Journal of Clinical Psychology*, 33, 333-344.

McKee, K.J., Whittick, J.E., Ballinger, B.B., Gilhooly, M.L.M., Gordon, D.S. Mutch, W.J. and Philp, I. (1997) Coping in family supporters of elderly people with dementia. *British Journal of Clinical Psychology*, 36, 323-340.

Montgomery, R.J.V. (1996) Advancing caregiver research: Weighing efficacy and feasibility of interventions. *Journal of Gerontology*, 51B, S109-S110.

Morris, L.W., Morris, R.G. and Britton, P.G. (1988) The relationship between marital intimacy, perceived strain and depression in spouse caregivers of dementia sufferers. *British Journal of Medical Psychology*, 61, 231-236.

Morrissey, E., Becker, J. and Rubert, M.P. (1990) Coping resources and depression in the caregiving spouse of Alzheimer patients. *British Journal of Medical Psychology*, 63, 161-171.

Narayan, S., Lewis, M., Tornatore, J., Hepburn, K., Corcoran-Perry (2001) Subjective responses to caregiving for a spouse with dementia. *Journal of Gerontological Nursing*, 27 (3), 19-28.

Neufeld, A., Harrison, M.J. (1998) Men as caregivers: reciprocal relationships or obligation? *Journal of Advanced Nursing*, 28 (5), 959-968.

National Institute for Health and Clinical Excellence (2006) *Dementia: Supporting people with dementia and their carers in social care*. London: National Institute for Health and Clinical Excellence.

Nolan, M., Walker, G., Nolan J., Williams, S., Polant, F., Curran, M. and Kent, B.C. (1996a) Entry to care: Positive choice or fait accompli? Developing a more proactive nursing response to the needs of older people and their carers. *Journal of Advanced Nursing*, 24, 265-274.

Nolan, M., Grant, G., Caldock, C. and Keady, J. (1994) *A framework for assessing the needs of family carers: A multidisciplinary guide*. University of Wales, Bangor.

O'Donnell, M.E. (2000) The long grey tunnel: the day to day experience of spouse caregivers of people with Alzheimer's disease. *Scholarly Inquiry for Nursing Practice*, 14 (1), 47-70.

O'Hare, R. (2009) Think Again: Making a better start after diagnosis. *Journal of Dementia Care*, 17 (4), 17-19.

O'Shaughnessy, M., Lee, K., Lintern, T. (2010) Changes in the couple relationship in dementia care: Spouses carers' experiences. *Dementia*, 9, 237-258.

Ohman, M., Soderberg, S. (2004) The Experiences of Close Relatives Living with a Person with Serious Chronic Illness. *Qualitative Health Research*, 14 (3), 396-410.

Orbell, S. (1996) Informal care in social context: A social psychological analysis of participation, impact and intervention in care of the elderly. *Psychology and Health*, 11 (1), 155-178.

Ott, C.H., Sanders, S., Kelber, S. T. (2007) Grief and personal growth experience of spouses and adult-child caregivers of individuals with Alzheimer's Disease and related dementias. *The Gerontologist*, 47 (6) 798-809

Page, S., Keady, J., Clarke, C.L. (2007) Models of community support for people with dementia. In Keady, J., Clarke, C.L., Page, S. (Eds.) *Partnerships in Community Mental Health Nursing and Dementia Care: Practice Perspectives*, Open University/McGraw Hill.

Pakenham, K.I. (1998) Couple coping and adjustment to multiple sclerosis in care receiver-carer dyads. *Family Relations*, 47 (3), 269-277.

Patterson, J.M., Garwick, A.W. (1994) The Impact of Chronic Illness on Families: A Family Systems Perspective. *Annals of Behavioural Medicine*, 16 (2), 131-142.

Patton, M.Q. (1999) Enhancing the quality and credibility of qualitative analysis. *Health Services Research*, Supp., 1189-1208.

Pearce, A., Clare, L. and Pistrang, N. (2002) Managing sense of self: Coping in the early stages of Alzheimer's disease. *Dementia*, 1, 173-192.

Perry, J. (2002) Wives Giving Care to Husbands with Alzheimer's Disease: A Process of Interpretive Caring. *Research in Nursing and Health*, 25, 307-316.

Phinney, A. (2006) Family strategies for supporting involvement in meaningful activity by persons with dementia. *Journal of Family Nursing*, 12 (1), 80-101.

Pinner, G. (2003) Attitudes of people with mild dementia and their carers towards disclosure of the diagnosis. *International Psychogeriatrics*, 15(3), 279-288.

Pinquart, M., Duberstein, P.R. (2005) Optimism, pessimism, and depressive symptoms in spouses of lung cancer patients. *Psychology and Health*, 20 (5), 565-578.

Pistrang, N., Clare, L., Baker, C. (1999) The helping process in couples during recovery from heart attack: A single case study. *British Journal of Medical Psychology*, 72, 227-237.

Proctor G. (2001) Listening to Older Women with Dementia: relationships, voices and power. *Disability and Society*, 16, 361-76.

Proctor, R., Martin, C. and Hewison, J. (2002) When a little knowledge is a dangerous thing...: a study of carers' knowledge about dementia, preferred coping style and psychological distress. *International Journal of Geriatric Psychiatry*, 17, 1133-1139.

Quayhagen, M.P. and Quayhagen, M. (1988) Alzheimer's stress: Coping within the caregiving role. *The Gerontologist*, 28 (3), 391-396.

Quayhagen, M.P., Quayhagen, M. (1996) Discovering life quality in coping with dementia. *Western Journal of Nursing Research*, 18 (2), 120-135.

Quinn, C., Clare, L., Pearce, A., van Dijkhuizen, M. (2008) The experience of providing care in the early stages of dementia: An interpretative phenomenological analysis. *Aging and Mental Health*, 12 (6), 769-778.

Quinn, C., Clare, L., Woods, B. (2009) The impact of the quality of relationship on the experiences and wellbeing of caregivers of people with dementia: A systematic review. *Aging and Mental Health*, 13 (2), 143-154.

Rabins, P.V., Fitting, M.D., Eastham, J., Zabora, J. (1990) Emotional Adaptation over Time in Care-givers for Chronically Ill Elderly People. *Age and Ageing*, 19, 185-190.

Reed, J., Clarke, C.L., Cantley, C., Stanley, D. (2007) Younger people with dementia: Emerging needs, multi-disciplinarity and the CMHN. In Keady, J., Clarke, C.L., Page, S. (Eds.) *Partnerships in Community Mental Health Nursing and Dementia Care: Practice Perspectives*, Open University/McGraw Hill.

Reed, J., Procter, S. (1995) *Practitioner research in Health Care: The Inside Story*. London: Chapman and Hall.

Rees, C.E., Bath, P.A., Lloyd-Williams, M. (1998) The information concerns of spouses of women with breast cancer: patients' and spouses' perspectives. *Journal of Advanced Nursing*, 28 (6), 1249-1258.

Roberto K., Richter J., Bottenberg D. and Campbell S. (1998) Communication patterns between caregivers and their spouses with Alzheimer's Disease: A case study. *Archives of Psychiatric Nursing*, 12, 202-8.

Robinson, C.A. (1993) Managing life with a chronic condition: The story of normalisation. *Qualitative Health Research*, 3 (1), 6-28.

Robinson, L., Clare, L., Evans, K. (2005) Making sense of dementia and adjusting to loss: Psychological reactions to a diagnosis of dementia in couples. *Aging and Mental Health*, 9 (4), 337-347.

Rodham, K., Rance, N., Blake, D. (2010) A qualitative exploration of carers' and 'patients' experiences of fibromyalgia: one illness, different perspectives. *Musculoskeletal Care*, 8 (2), pp. 68-77.

Sabat, S.R. and Collins, M. (1999) Intact social, cognitive ability, and selfhood: A case study of Alzheimer's disease. *American Journal of Alzheimer's disease*, 14 (1), 11-19.

Sabat, S.R. and Gladstone, C.M. (2010) What intact social cognition and social behaviour reveal about cognition in the moderate stage of Alzheimer's disease: A case study. *Dementia*, 9 (1), 61-78.

Sabat, S.R. and Harre, R. (1992) The construction and deconstruction of self in Alzheimer's disease. *Ageing and Society*, 12, 443-461.

Saleebey, D. (1996) The strengths perspective in social work practice: Extensions and cautions. *Social Work*, 41 (3), 296-305.

Sandberg, J., Eriksson, H. (2007) 'The hard thing is the changes': The importance of continuity for older men caring for their wives. *Quality in Ageing*, 8 (2), 5-16.

Schwartz, L. and Ehde, D.M. (2000). Couples and chronic pain. In Schmaling, K.B. & Sher, T.G. (Eds.) *The psychology of couples and illness*. Washington DC: American Psychological Association

Searson, R., Hendry, A.M., Ramachandran, R., Burns, A., Purandare, N. (2008) Activities enjoyed by patients with dementia together with their spouses and psychological comorbidity in carers. *Aging and Mental Health*, 12 (2), 276-282.

Sheard, D. (2004) Bringing relationships into the heart of dementia care, *Journal of Dementia Care*, Jul/Aug, 22-24.

Shields, C.G., Travis, L.A. and Rousseau, S.L. (2000) Marital attachment and adjustment in older couples coping with cancer. *Aging and Mental Health*, 4, 223-33.

Silverman, D. (2001) *Interpreting qualitative data: Methods for analysing talk, text and interaction*. Second edition. Sage Publications, London.

Skeil, D. (1995) Patients feelings about patients. In Reed, J. & Procter, S., (1995) *Practitioner Research in Health Care: The Inside Story*. London: Chapman & Hall.

Smith, J.A. (1995) Semi-structured interviewing and qualitative analysis. In Smith, J.A, Harre, R., Van Langenhove, L. (Eds.) *Rethinking Methods in Psychology*. London: Sage Publications Ltd.

Smith, J.A., Osborn, M. (2003) Interpretative phenomenological analysis. In Smith, J. (Ed.) *Qualitative Psychology: A Practical Guide to Research Methods*. London: Sage Publications Inc.

Smith, J.A., Jarman, M., Osborn, M. (1999) Doing interpretative phenomenological analysis. In, Murray, M. and Chamberlain, K. (Eds.) *Qualitative Health Psychology: Theories and Methods*. London: Sage.

Smith, P. (2009) The family caregivers journey in end of life care: Recognising and identifying with the role of carer. *International Journal of Disability and Human Development*, 8 (1), 67-73.

Sormanti, M., Kayser, K. (2000) Partner Support and Changes in Relationships During Life-Threatening Illness: Women's Perspectives. *Journal of Psychological Oncology*, 18 (3), 45-66.

Stanton, A.L., Revenson, T.A., Tennen, H. (2007) Health Psychology: Psychological adjustment to chronic disease. *Annual Review of Psychology*, 58: 565-592.

Steadman, P.L., Tremont, G., Duncan Davis, J. (2007) Premorbid relationship satisfaction and caregiver burden in dementia caregivers. *Journal of Geriatric Psychiatry and Neurology*, 20 (2), 115-119.

Steinglass, P. and Horan, M.E. (1987) Families and chronic medical illness. *Journal of Psychotherapy and the Family*, 3, 127-142.

Strawbridge, W.J., Wallhagen, M.I., Ngoc Thai, J., Shema, S. (2009) The influence of spouse lower cognitive function on partner health and well-being among community-dwelling older couples: Moderating roles of gender and marital problems. *Aging and Mental Health*, 13 (4), 530-536.

Swensen, C.H. and Trahaug, G. (1985) Commitment and the long-term marriage relationship. *Journal of Marriage and the Family*, 47 (4), 939-945.

Szabo, V. and Strang, V.R. (1999) Experiencing control in caregiving. *Journal of Nursing Scholarship*, 31, 71-75.

Theut, S.K., Jordan, L., Ross, L.A. and Deutsch, S.I. (1991) Caregiver anticipatory grief in dementia: A pilot study. *International Journal of Aging and Human Development*, 33 (2), 113-118.

Thommessen, B., Aarsland, D., Braekhus, A., Oksengaard, A.E., Engedal, K., Laake, K. (2002) The psychosocial burden on spouses of the elderly with stroke, dementia and Parkinson's disease. *International Journal of Geriatric Psychiatry*, 17: 78-84.

Thomson, E., Williams, R. (1982) Beyond wives' family sociology: A method for analysing couple data. *Journal of Marriage and Family*, 44 (4), 999-1008.

Todres, L and Galvin, K (2006) Caring for a partner with Alzheimer's disease: intimacy, loss and the life that is possible. *International Journal of Qualitative Studies on Health and Well-being*, 1, 50-61.

Trigg, R., Jones, R.W., Skevington, S.M. (2007) Can people with mild to moderate dementia provide reliable answers about their quality of life? *Age and Ageing*, 36, 663-669.

Turner, A., Barlow, J. and Ilbery, B. (2002) Play hurt, live hurt: Living with and managing osteoarthritis from the perspective of ex-football players. *Journal of Health Psychology*, 7 (3), 285-301.

Vernooij-Dassen, M., Derksen, E., Scheltens, P., Moniz-Cook, E. (2006) Receiving a diagnosis of dementia: The experience over time. *Dementia*, 5 (3): 397-410.

Vess, J., Moreland, J. and Schwebel, A.I. (1985) Understanding family role relocation following a death: A theoretical framework. *Omega-Journal of Death and Dying*, 16 (2), 115-128.

Walster, E., Walster, G.W. and Berscheid, E. (1978b) *Equity theory and research*. Boston: Allyn and Bacon.

Welleford EA, Harkins SW, Taylor JR. (1995) Personality change in dementia of the Alzheimer's type: Relations to caregiver personality and burden. *Experimental Aging Research*, 21, 295-314.

Westius, A., Andersson, L., Kallenberg, K. (2009) View of life in persons with dementia. *Dementia*, 8 (4), 481-499.

Williams R, Briggs R, Coleman P. (1995) Carer-related personality changes associated with senile dementia. *International Journal of Geriatric Psychiatry*, 10, 231-236.

Williamson, G.M. and Schulz, R. (1993) Coping with specific stressors in Alzheimer's disease caregiving. *The Gerontologist*, 33 (6), 747-755.

Wimo, A., Prince, M. (2010) *World Alzheimer Report 2010: The Global Economic Impact of Dementia*. Alzheimer's Disease International, London.

Woods, R.T. (2001) Discovering the person with Alzheimer's Disease: Cognitive and emotional aspects. *Aging and Mental Health*, 5, S7-S16.

Wright, L.K. (1991) The Impact of Alzheimer's Disease on the marital relationship. *The Gerontologist*, 31, 224-37.

Wright, L.K. (1993) *Alzheimer's Disease and Marriage*. London: SAGE Publications Inc.

Wuest J, King Ericson P, Noerager Stern P. (1994) Becoming Strangers: the changing family caregiving relationship in Alzheimer's disease. *Journal of Advanced Nursing*, 20, 437-443.

Yarry, S.J., Judge, K.S., Orsulic-Jeras, S. (2010) Applying a strengths-based intervention for dyads with mild to moderate memory loss: Two case examples. *Dementia*, 9 (4), 549-557.

Zarit, S.H. and Edwards, A.B. (2008) Family caregiving: Research and clinical intervention. In Woods, R.T., Clare, L. (Eds.) *Handbook of the clinical psychology of ageing*. Chichester: Wiley.

Zarit, S.H., Johansson, L., Jarrott, S.E. (1998) Family Caregiving: Stresses, Social Programs and Clinical Interventions. In Nordhus, I.H., VandenBos, G.R., Berg, S. and Fromholt, P. (Eds.) *Clinical Geropsychology*. Washington DC: American Psychological Association.

Appendix One

Sample Demographics

	PWD 1	PWD 2	PWD 3	PWD 4
Sex	Male	Male	Male	Male
Age	84	64	79	79
Carer Age		73	69	69
Time since diagnosis	22 m	67 m	20 m	22 m
Diagnosis	AD	MID	AD	VAD
Living	SA	H	H	SA
Years married	37	43	50	50
1st/2nd marriage	2 nd	1 st	1 st	1 st
Children	2 step-children	1	3	1
1st interview	25.10.04	15.11.04	21.2.05	14.3.05
2nd interview	17.3.05	4.4.05	9.5.05	11.8.05
Time between interviews	5 m	5 m	3 m	5 m

Table 1: Sample demographics for Couples 1-4

<p><u>Couple 1</u> Couple 1 married in 1967, a second marriage for them both. Carer 1 has 2 children. They did not have any children together. They now live in sheltered accommodation in North Wiltshire. PWD 1 was diagnosed with Alzheimer's Disease in 2002.</p>
<p><u>Couple 2</u> Couple 2 married in 1961. They have one son. They live in their own house in North Wiltshire. PWD 2 was diagnosed with Multi-Infarct Dementia in 2003.</p>
<p><u>Couple 3</u> Couple 3 married in 1955. They have three children together. They live in their own house in North Wiltshire. PWD 3 was diagnosed with Alzheimer's Disease in 2002.</p>
<p><u>Couple 4</u> Couple 4 married in 1955. They have one daughter. They now live in sheltered accommodation in North Wiltshire. PWD 4 was diagnosed with Vascular Dementia in 2003.</p>

Table 2: Background information for Couples 1-4.

Footnote.
Time since diagnosis: 9 m (months). **Diagnosis:** AD (Alzheimer's disease), MID (Multi-infarct dementia), VAD (Vascular dementia). **Living:** H (living in own home), SA (living in sheltered accommodation). **Time between interviews:** 9 m (months).

	PWD 5	PWD 6	PWD 7	PWD 8
Sex	Female	Male	Female	Male
Age	70	65	70	63
Carer age	77	61	74	61
Time since diagnosis	28 m	9 m	23 m	18 m
Diagnosis	AD	Mixed dementia	AD	AD
Living	H	H	SA	H
Years married	49	40	41	43
1st/2nd marriage	1 st	1 st	2 nd	1 st
Children	2	1	3	4
1st interview	4.4.05	12.5.05	13.6.05	20.6.05
2nd interview	15.8.05	22.8.05	26.9.05	17.10.05
Time between interviews	4 m	3 m	3 m	4 m

Table 3: Sample demographics for Couples 5-8.

<p><u>Couple 5</u> Couple 5 married in 1956. They have two children. They live in their own house in North Wiltshire. PWD 5 was diagnosed with Alzheimer's Disease in 2002.</p>
<p><u>Couple 6</u> Couple 6 married in 1965. They have one daughter. They live in their own house in North Wiltshire. PWD 6 was diagnosed with Mixed Dementia in 2004.</p>
<p><u>Couple 7</u> Couple 7 married in 1963: a second marriage for them both. PWD 7 has two sons from her first marriage and they have a daughter together. They now live in warden-controlled flats in North Wiltshire. PWD 7 was diagnosed with Alzheimer's Disease in 2003.</p>
<p><u>Couple 8</u> Couple 8 married in 1962. They have four children together. They live in their own house in North Wiltshire. PWD 8 was diagnosed with Alzheimer's Disease in 2004.</p>

Table 4: Background information for Couples 5-8.

Footnote.

Time since diagnosis: 9 m (months). **Diagnosis:** AD (Alzheimer's disease), MID (Multi-infarct dementia), VAD (Vascular dementia). **Living:** H (living in own home), SA (living in sheltered accommodation). **Time between interviews:** 9 m (months).

	PWD 9	PWD 10	PWD 11	PWD 12
PWD Sex	Male	Male	Female	Female
PWD Age	64	72	74	77
Carer age	52	64	74	75
Time since diagnosis	9 m	15 m	74 m	54 m
Diagnosis	AD	AD	AD	AD
Living	H	H	H	H
Years married	6	24	52	54
1st/2nd marriage	2 nd	2 nd	1 st	1 st
Children	He 2, she 3	He 4, she 3	2	1
1st interview	6.9.07	6.9.07	2.10.07	13.12.07
2nd interview	13.11.07	11.12.07	11.11.07	10.01.08
Time between interviews	2 m	3 m	1 m	1 m

Table 5: Sample demographics for Couples 9-12.

<p><u>Couple 9</u> Couple 9 married in 2001, a second marriage for them both. PWD 9 has 2 children and his wife has 3. They live in their own house in Gloucestershire. They were the youngest couple in the sample, both in their early 50's. PWD 9 was diagnosed with Alzheimer's Disease in 2007.</p>
<p><u>Couple 10</u> Couple 10 married in 1983: a second marriage for them both. They live in their own house in North Wiltshire. PWD 10 has four children and his wife had three children. PWD 10 was diagnosed with Alzheimer's Disease in 2006.</p>
<p><u>Couple 11</u> Couple 11 married in 1955. They have two daughters. They live in their own house in North Wiltshire. PWD 11 was diagnosed with Alzheimer's Disease in 2001.</p>
<p><u>Couple 12 – Couple C</u> Couple 12 married in 1953. They have one daughter. They live in their own house in North Wiltshire. PWD 12 was diagnosed with Alzheimer's Disease in 2003.</p>

Table 6: Background information for Couples 9-12.

Footnote.

Time since diagnosis: 9 m (months). **Diagnosis:** AD (Alzheimer's disease), MID (Multi-infarct dementia), VAD (Vascular dementia). **Living:** H (living in own home), SA (living in sheltered accommodation). **Time between interviews:** 9 m (months).

Appendix Two

Interview Schedule

Interview schedule for first interview

The schedule for the first interview fell into three broad areas which addressed the participant's relationship with their spouse, their experiences of dementia and the ways in which they tried to cope with dementia.

Part 1:

Tell me about your relationship with your spouse

- How long have you been together?
- How did you both meet?
 - Are there things that you and your spouse like doing together?
 - Do you tend to do things together or are you quite independent of one another?
 - Can you give an example?
- How would you describe your personality?
- How would you describe your spouse's personality?
- How close would you say that you and your spouse are?
- How much do you feel you can discuss things with them?
- How much do you think your spouse understands how you feel?
- How happy are you with communication between you two?

Each initial interview began by the researcher asking the participant an ice-breaker question, which in this case was how they met and got together with their spouse. This section of the interview allowed the researcher to gain an understanding of the participants and their relationship with their spouse as they saw it. By asking them about their past, i.e. how they first met, participants were put in the 'expert' position from the outset. They were able to describe their relationship over the years and the routines they had established, often over several years of marriage. This section provided a tentative baseline for the researcher to get to know the couples, what they were like as individuals and how they viewed their life as part of a couple. These questions also sought to reinforce their dignity of personal identity which is embedded in their life history and relationships (Nordenfelt 2004).

Part 2:

Tell me about your experience of dementia

- Were there any signs that you (your spouse) were developing dementia?
 - Prompt: what were they?
- How did you feel when you (your spouse) were diagnosed?
- Who told you?
- How were you told?
- What were you told?
- Did you talk about it together?
- Was this difficult?
 - Has the way you interact with your spouse changed since the diagnosis?
 - How? (personality, communication, closeness)
 - Have you noticed any other changes?
 - Have you attempted to adjust to these new changes? If so, how?
- Has the diagnosis affected your plans for the future?
- Is caring for spouse part of marriage?

What were your expectations of marriage at this point in your life?

This part of the interview focused on the participant describing their experience of dementia. Participants were asked to think about the initial impact of the diagnosis and also if it had affected their interactions with their spouse in the past and presently. This section addressed objectives surrounding how participants describe the impact of mild dementia on their relationship and lives and any conflicts that may have arisen. By comparing it with how participants describe themselves and their spouses in the first part of the interview schedule, the researcher was able to identify any changes. Differences between people with mild dementia and their spouses also often became apparent at this point.

Part 3:

How do you cope with dementia?

- Tell me something about dementia that frustrates you?
 - When you feel this way, are there things that you can do that help you to cope with this feeling?
 - Is this something you have always done when you have felt this way?
- How do you feel about coping with such frustrations in the future?
- Do you find yourself blaming yourself or your spouse?
- What do you find that helps the most / least?
- Can you think of other ways that might be useful?
- What things do you feel would make your situation easier?

The final part of the interview schedule covered how participants attempted to cope with mild dementia. This allowed the researcher to address the coping objectives and encouraged the participants to be aware of the techniques they had employed to help them cope.

Interview schedule for second interview

A second interview was scheduled in order to discuss further the issues that were brought up in the first interviews, and to offer the participants some continuity in the process. It was hoped that this continuity and contact with the researcher would elicit more in-depth discussion because participants were given the chance to develop a sense of familiarity and trustworthiness towards the researcher.

This schedule for the second interview included a list of generic questions (see below) but also included questions pertinent to each couple that were created from the preliminary analysis of their first interviews.

1. What did you think about the summary letter? Do you have any questions or was there anything that you didn't agree with?
2. Some people have likened the process of accepting that they or a loved one has memory problems, to the grieving process. This involves stages of denial, anger, depression, acceptance and reconstruction (including a brief definition of these terms).
 - a. What do you think about that idea?
 - b. Do you recognise any of these stages in your experience?
 - c. Have you stopped at any?
 - d. Did you miss any?
3. Is it important to have other support, namely friends and family, other than your spouse? Why?
4. When you socialise, do you stay together or do you talk to different people? Why?
5. Is there anything that you would like to do, such as visit a certain place, do an activity or something like that? If so, do you think you will achieve that? If not, what are the barriers?

6. How much do you feel like yourself? / Does your spouse feel like him/herself?
7. How much do you feel emotionally supported by your spouse? What about friends and family?
8. Do you think 'Why us?' is an initial reaction to the news that you / your spouse has memory problems? Or do you still feel this way? Or do you not feel that at all?
9. How do you think the memory problems (yours or spouses) have impacted your life and how have they impacted your spouse's life?
10. How do you feel about the service you have received from the Memory Clinic, Clinical Trials and research?
11. Do you feel like a romantic couple?
12. Love life. Has Alzheimer's made any difference to that? Action or talking about it?
13. Have the roles or responsibilities held by you and your spouse changed at all? i.e. household chores, finance, social organiser.
14. When you first found out about the memory problems, did you wonder why it had happened?

Throughout all interviews, time was given to participants if they were having difficulty remembering something or getting the right words to describe what they wanted to say. Prompts were given if appropriate, and the researcher endeavoured to be supportive without leading the discussion. This was achieved by asking questions about how they felt, or what did they mean by that. This served to validate what they were saying because the researcher showed genuine interest by asking them to explain further.

Appendix Three

Information letter and consent form

TAKING PART IN RESEARCH

INFORMATION FOR PATIENTS ABOUT THE STUDY

Study Title: An investigation into the impact of dementia and how couples cope with this.

**February 2004
Version One**

You are being invited to take part in a research project. Here is some information to help you decide whether or not to take part. Please take time to read the following information carefully and discuss it with friends, relatives and your GP if you wish. Please ask us if there is anything you do not understand or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

What is the purpose of the study?

The aim of this study is to improve theoretical understanding of how romantic couples (people with dementia and their spouses) experience dementia and how they cope with it.

Why have I been chosen?

In order to determine how couples experience dementia, it is necessary to include participants that have either been diagnosed with dementia or are a spouse of someone who has. Both of you should be willing to take part in order to be entered into the study.

Who is organising the study?

Louise Foster, a Research Assistant at Kingshill Research Centre, Swindon. This piece of research will form part of her PhD in Psychology at University of Bath.

What will happen to me if I take part?

A Research Assistant will visit you at your home or meet you at Victoria Hospital, depending on your preference. You will meet with or talk to the Researcher three times during the study.

1. You will each be interviewed separately by the Researcher. The same issues will be covered in both of your interviews but what you talk about will very much be determined by what you feel is important.
2. Once the researcher has transcribed your interview, you will meet with them or talk to them over the telephone to clarify any questions they or you may have. Sometimes questions arise while interviews are transcribed.

3. A summary will then be written about your interviews and you will each be sent a copy. Once you have had the time to read this, you will be contacted by the Researcher who will ask whether the summary accurately represents what you said. This will give you the opportunity to further clarify your thoughts, if necessary, and allow the Researcher to ensure she has understood you correctly.

A report will be written about how couples experience and cope with dementia. Neither you nor your personal details will be identified in any such reports.

It is up to you to decide whether to take part or not. Even if you do decide to take part, you are free to withdraw at any time and without giving a reason. This will not affect the standard of care you will receive. Your doctor will not be upset if you decide not to take part.

Are there any disadvantages in taking part in this study?

There are no disadvantages to taking part in this study.

What are the possible benefits of taking part?

There are no direct benefits to you from taking part in this study. However, you may find that talking about your experiences related to memory problems is beneficial for you.

Are there any restrictions on what I might eat or do?

There are no restrictions on what you might eat or do. Feel free to carry on as normal with regard to your individual routine.

Confidentiality – who will know I am taking part in the study?

Throughout the study, the researcher may need to access your medical notes in order to record that you took part in the research and for demographic information. Any information that is collected by these means will be kept strictly confidential. Any information about you that leaves the hospital will be anonymised so that you cannot be recognised from it. This is stated on the consent form that you will need to sign before you can take part in the project.

Consumers for Ethics in Research (CERES) publish a leaflet entitled 'Medical Research and You'. This leaflet gives more information about medical research and looks at some questions you may want to ask. A copy may be obtained from CERES, PO Box 1365, London N16 0BW.

LREC Approval

This study has been reviewed by Swindon Research Ethics Committee.

What will happen to the results of the study?

The Research Assistant will write up this research for her thesis in support of her PhD in Psychology. She also aims to publish the results of this research in the form of a presentation at a conference and also a research paper/s in a suitable journal. The 'Research Focus Group' that consists of people with dementia and their carers, will be updated with research progress as they are involved in the planning and execution of research at Kingshill Research Centre. Other local groups will be told about the outcome of this research where it is thought to be of benefit to them. It is hoped that a leaflet will also be produced regarding coping techniques to be left in waiting rooms at Specialist outpatient clinics.

Contact for further information

For further information, please contact Louise Foster on 01793 437519.

Thank you for taking the time to read this information sheet

CONSENT FORM

Project title: An investigation into the impact of dementia and how couples cope with this.

Please read the information below, initial each point if you agree and sign the bottom to say that you agree with it.

1. I confirm that I have read and understand the information sheet for the above study.
2. I agree that my interview data can be used for Phase's One and Two of the project.
3. I understand that my participation is voluntary and that I am free to withdraw at any time without my medical care or legal rights being affected.
4. I am willing to allow access to my medical records but understand that strict confidentiality will be maintained. The purpose of this is to check basic medical details.
5. I agree that the interview can be audio-taped and I understand that these tapes will be wiped at the end of the project.
6. I agree to take part in the above study.

_____ Name of patient	_____ Date	_____ Signature
_____ Name of person taking consent (if different from researcher)	_____ Date	_____ Signature
_____ Researcher	_____ Date	_____ Signature

Appendix Four

Example of a summary letter

PWD 10
Address

Date

Dear PWD 10,

I hope you are well and that you are enjoying a nice autumn. After speaking to Carer 10 last week, we have agreed that I will come again to do another interview with each of you on 11th December 2007, it that's OK with you.

This letter will include a summary of what we talked about last time (Sept) so that you can have a look through before we meet in December. This is my interpretation of what we talked about. The aim of this letter is to ensure I am representing your thoughts correctly. If I have not done this or if you have any questions about this summary please make a note of them and we will chat about them when I see you. Additionally, if you think of something else that you want to talk about that we did not discuss last time, then please feel free to bring that up at our next meeting too.

I am sending each of you a letter separately because the information included about the interviews is confidential. If you would like to share it with Carer 10 then this is fine but please do not do so until I have seen you both again in December. This will ensure that in the next interview neither of you will be affected by something the other one said in their interview. I hope you understand that I have to try and control for these variables as much as I can. Equally, you are under no pressure to share this with Carer 10 if you do not wish to. If this does not make sense, please contact me (01793 437519) and I will try to explain it more clearly!

Your interview:

1. I asked you to tell me about your life. You said this is your second marriage and that your first wife left you.
2. You have been married to Carer 10 for twenty four years now.
3. You fairly recently moved house and I asked you how the move has been for you. You said it was a bit strange at first because it was harder to find things to do.
4. You have a part time job which you enjoy. You either drive or cycle to work (usually cycle) and it is quite involved. You said you will give it up at some point but at the moment you enjoy the company.
5. You said you like to get out and about and do things. Since Carer 10's Mum died last year you have been able to do a lot more, which you have enjoyed.

6. You said that sometimes you still find it a bit quiet at your new house.
7. You told me about how you got this house, by talking to the people next door who told you that this one would be for sale in a few weeks.
8. You said sometimes it feels a bit too quiet here. I asked you if you felt unsettled and you said yes. You still felt like you don't know anyone at your new place which is a change from where you used to live because you knew everyone.
9. You really enjoy work although one of your colleagues – a very nice and jolly lady – had left so you weren't sure if the working environment would change as a result. You said at first it seemed very quiet.
10. You said you've never had a good memory.
11. You said that most days you are alright but some days you have problems. We discussed that it is different for everyone and agreed that this makes it difficult.
12. You said that sometimes you get down thinking about it but you try to just get on with things. You said it is a depressing thing to happen to you.
13. We talked about how you came to find out you had memory problems and you said you attended the Memory Clinic because it was in the family. You had done a number of assessments and one day you felt you had done much worse than normal. It was following this that you were told.
14. You said you were asked to spell a word backwards and although you had done it previously you could not think how to do it.
15. You said you had been thinking about how much time you might have where you are going to be like you are now.
16. You said sometimes you have times where you cannot think how to do something. You said you get confused doing jobs and have to stop and start to try and remember what to do. Sometimes Carer 10 says 'Oh give it to me for God's sake'.
17. I asked you if you worried whether you would be able to do something and you said yes. You said you worry about things which make you depressed, but you don't want to be depressed, you want to be like your usual self.
18. You had seen your ex-wife the day before we did this interview and you said it was unsettling to see her. You said you still cannot be friends with her.
19. We then talked about the people you have met through the Victoria Hospital groups you attended. You said you feel sorry for some of the people, especially one guy who is a lot younger than you but also much worse memory-wise. You said he is a very intelligent guy but he finds it hard to talk to people because he gets so frustrated with himself.
20. You said that you occasionally go out for dinner with them, sometimes to the [pub] which you really enjoy. You said that you three couples have really clicked.
21. I asked you if it helps to spend time with them because they're going through the same thing. You said it does help – you said you can't control what is going on in your head. You said that's the problem. It would be lovely if you could say 'I've got to think about that' and come back to it later, but you said you can't really do that.

22. You said you have felt things have been easier since you half-retired. You have more time and freedom to do what you want to do.
23. You said that Carer 10's Mum left you both some money so that has made life even easier for you.
24. I asked you if your memory stops you from doing anything and you said no.
25. You said you had a good childhood although your family was poor and you used to sleep at the end of your parents' bed. You said you had lots of laughs.
26. I asked you what you thought initially when the doctor told you you have memory problems. You said you knew you were having some difficulty so you were expecting it. Still it was a bit of a shock because most of the time you are alright.
27. You said when you started to struggle with the memory assessments, it was suggested that you could try some medication which you did.
28. You said you felt depressed when you struggled with the assessments, but you have since gone back and done them OK. You said you hate being depressed.
29. You said you also feel a bit lonely sometimes.
30. You have four daughters who live fairly locally and have all done well for themselves. You see them every week.
31. I asked if you felt they supported you and you said yes but you're not in each others pockets and they have children and issues of their own to deal with.
32. I asked you if there was anything about your memory that frustrates you and you said sometimes you just can't remember things. You go to speak and can't get the words out. You said this doesn't happen all the time. I asked you if this had anything to do with you feeling anxious and you said that you do get anxious.
33. You said Carer 10 is great. We talked about what you would do if something was worrying you and you said you wouldn't always discuss it with her straightaway but you would always tell her in the end.
34. You said she knew that morning that you were feeling down and she asked you about it. She tries to encourage you to look on the positive side and you do try to do this. You feel happy talking to her.
35. You said on the whole, you can be alright for weeks and then have a couple of bad days.

In a nutshell, that is what we covered in your interview!

Please contact me if you have any questions about this letter. My direct line is 01793 437519. Otherwise, I will see you on the 11th December.

Thank you for taking the time to read this. Looking forward to seeing you in December.

Best wishes,

Louise Foster

Appendix Five

Ethical approval



Swindon Research Ethics Committee (REC)
Kennet and North Wiltshire Primary Care Trust
Southgate House
Pans Lane
Devizes
Wiltshire
SN10 5EQ

Direct Line: 01380 733767
Fax: 01380 733779

13 May 2004

REC reference number SW 93/2003 please quote this number on all correspondence
--

Miss Louise Cima
Kingshill Research Centre
Victoria Hospital
Okus Road
Swindon
Wiltshire

Dear Miss Cima

Full title of study: An investigation into the impact of dementia and how couples cope with this
REC reference number: SW 93/2003

Thank you for your letter of 18 March 2004 , responding to the Committee's request for further information on the above research.

The further information was considered at the meeting of the Swindon Research Ethics Committee held on 11 May 2004. A list of the members who were present at the meeting is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm ethical approval for the above research on the basis described in the application form, protocol and supporting documentation.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Protocol
Consent Form
Patient Information Sheet

all submitted with original application dated 23 February 2004.

Management approval

The study may not commence until final management approval has been confirmed by the organisation hosting the research.

Local research collaborators who will be participating in this research must obtain management approval from the relevant host organisation before commencing any research procedures. Where the collaborator does not have a substantive contract with the host organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees in the UK (May 2004) and complies fully with national standard operating procedures.

Yours sincerely,

Kirsten Peck

**Kirsten Peck
Administrator
Swindon Research Ethics Committee**

**List of members present
at the meeting of
Swindon Research Ethics Committee
on 11 May 2004**

Mr Godfrey Fowler - Chair
Rev Dr Georgie Hawley
Rev Stephen Henderson
Mrs Wendy Griffiths
Mrs Maureen Lloyd
Dr Elizabeth Price
Mrs Kirsten Peck - Administrator